

DOCTORAL THESIS

‘Schizophrenia’: a Crisis of Meaning

A heuristic exploration of the psychotherapeutic experiences of those who have a ‘schizophrenia’ diagnosis

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‘Schizophrenia’: a Crisis of Meaning

**A heuristic exploration of the psychotherapeutic experiences of those who have a
‘schizophrenia’ diagnosis**

By

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A thesis submitted in partial fulfilment of the requirements for the degree of PsychD
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Abstract

The empirical aim of this heuristic study was to explore the psychotherapeutic experiences of those with a 'schizophrenia' diagnosis. The epistemological aim was to deconstruct the structures of knowledge underpinning the diagnosis. The 'personal knowledge' drawn from the researcher's own experience of working as a psychotherapist and filmmaker with individuals who had the diagnosis, and of being a psychiatric patient in the past, was used as a way of furthering these aims. Along with the work of Moustakas and Polanyi, key discourses used were Heidegger, Laing and contemporary critical clinical discourses.

Eight participants with a 'schizophrenia' diagnosis took part in open-ended, conversational interviews that yielded substantial detail about the phenomenon. A multi-perspective chronological narrative of early life experience, 'schizophrenic' breakdown, treatment and recovery emerged during the analysis of data, and is preserved in the composite depiction of the group experience. It was found that exploring the meaningfulness of experiences was a core driver of recovery, and psychotherapy was most helpful when it facilitated this exploration. By contrast, psychotherapy, and treatment as a whole, that obstructed this exploration were found unhelpful.

These findings led to the argument that, what is termed 'personal meaning', may be a key factor in recovery from 'schizophrenia', and psychotherapy that was helpful seemed characterised by Heidegger's concept of 'anticipating care'. Treatment governed by 'medical meaning' and 'intervening care', meanwhile, are argued to prolong a crisis of 'personal meaning', and potentially facilitate an 'acute' phase of 'schizophrenia', rather than recovery. This conclusion raises critical questions about NICE guidelines for 'schizophrenia', which seem rooted in 'medical meaning intervening care'. As well as facilitating an 'understanding' approach (in Heidegger's sense) to researching experience, one key outcome arising from the researcher's autobiographical connection to the research was learning more about his own experiences, and how to speak about them.

Keywords: schizophrenia/diagnosis/trauma/experience/meaning/psychotherapy/recovery

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Profound thanks are also due to my supervisors, Prof. Del Loewenthal and Dr Julia Cayne, whose inspiration and uncompromising feedback guided me through the process of carrying out this study. Without their shepherding influence I might well have been writing this acknowledgement ten years hence.

Above all, my deepest thanks to my wife and children for putting up with me for the six years it took to complete this study. Without their patience, encouragement and unwavering support, this study would have been abandoned long ago.

Ethical approval

The research for this project was submitted for ethics consideration under the reference PT 09/025 in the department of Human and Life Sciences and was approved under the procedures of the University of Roehampton's Ethics Committee on 03/09/2010. Further details of this approval can be found in the appendix, along with a sample consent form.

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Additional materials**(Back cover insert)**

There is a Fault in Reality. (2010) Film. Directed by Tom Cotton. [DVD] UK: Tigerlily Films.

Notes on the text

Data analysis and findings

All participants took part on the condition of anonymity. Each participant has been given a coding, for example, (H). Each paragraph and line of transcribed interview was numbered. For example, (H:21:1) refers to Participant H, paragraph 21, line 1.

Where verbatim in the findings chapter is presented in an indented 10 point text block, codings are given at the start of each segment. Where verbatim is edited, each edit starts with a new codings reference. The exception is where a few words may have been edited out for clarity. For example:

(D:16:1) I think the whole problem, the reason why I got the diagnosis of paranoid schizophrenia was the fact that I was escaping from a life that I was born into... (D:16:7) [I]f I didn't actually break out from my... mental confine, and the social aspects of my life at the time, I would have committed suicide.

Where verbatim is incorporated into the main text, the codings reference is given at the end, like a book reference. This referencing system is also used where verbatim is summarised as this extract from pp132-133 exemplifies:

(G) feared revealing the 'undesirable aspects' of herself associated with traumatic experiences (G:103:3), which made intimacy with another person difficult (G:103:1).

Where a larger section of verbatim is referred to, or summarised, it appears like this extract from p133:

(B) thought his second residential TC therapist was interested in him and respected him, which made him feel worthwhile, safe, and less frightened (B:98:1-B:100:1).

However, there are places in the findings, in particular the composite depiction and the creative synthesis, where an experience is broadly referred to. In this case just the participant coding is used. For example, on pp117-118:

This included being raped (C,E,F,G), experiencing relationship breakdown (A,E,F) being bullied (D,F,G,H), attempting suicide (H), parental divorce (A), and the pressures of early adult life (A,B,D,F,G,H).

This system is also used in Chapter 1 and the discussion in Chapter 7. This system enables the reader to trace all data referred to back to participant's individual depictions and exemplary portraits, which can be found in the appendix.

All chapters

Where historical context is required for a specific reference the original publication date is shown after the date of the edition referenced. For example, (Heidegger 2008 [1926]).

Footnotes are kept to a minimum. However, they contain information that will be useful to read.

Glossary of terms

ADHD – Attention Deficit Hyperactivity Disorder
APA – American Psychiatric Association
BACP – British Association of Counselling and Psychotherapy
BPD – Borderline Personality Disorder
CBT – Cognitive Behavioural Therapy
CBTp - Cognitive Behavioural Therapy for psychosis
CMHT – Community Mental Health Team
DA – Discourse Analysis
DBT – Dialectical Behaviour Therapy
DID – Dissociative Identity Disorder
DSM – Diagnostic and Statistical Manual of Mental Disorders
DSM-IVTR – Revised fourth edition of DSM
ECT – Electro Convulsive Therapy
EP – Empirical Phenomenology
HVN – The Hearing Voices Network
IPA - Interpretive Phenomenological Analysis
IV – Intervoice (an affiliate of HVN)
MRI – Magnetic Resonance Imaging
NCCMH - National Collaborating Centre for Mental Health
NICE – National Institute of Clinical Excellence
NSUN – National Survivor User Network
PA – Philadelphia Association
PC Therapy – Personal Construct Therapy
PET scan – Positron Emission Tomography scan
RCT – Randomised Control Trial
TC – Therapeutic Community
UKCP – United Kingdom Council for Psychotherapy
WHO – World Health Organisation

Chapter 1

Introduction

1.1. Study overview

In this heuristic study, a detailed depiction was sought of the psychotherapeutic experiences of those with a ‘schizophrenia’¹ diagnosis. The aim to research this phenomenon empirically arose from a ‘passionate concern’ (Moustakas 1990:27) within the researcher’s own experience. Rather than being a potential source of ‘bias’, in heuristic research this kind of ‘autobiographical connection’ is required (p43) in order to access ‘personal knowledge’ (Polanyi 1969) both about the researcher’s self, and the phenomenon researched (McLeod 2001:83). This connection took several forms during the course of this study.

While researching a Wellcome Trust funded documentary film about the experiences of those with the diagnosis² in the early stage of this study, it became apparent that psychotherapy had been an important facilitator of recovery for some people. Yet there was little qualitative detail available in published literature from the perspective of the *experiencing person* about what was helpful, or *how* they thought recovery had been enabled. Wanting to explore this issue more deeply led to working as a psychotherapist and project manager of a residential Therapeutic Community (TC) for those with the diagnosis. During this experience, a deeper appreciation of the root of this ‘passionate concern’ developed, which derived from an earlier experience of being a psychiatric patient, hospitalised in my early twenties with a drug-related breakdown that had psychotic features³. While never diagnosed with ‘schizophrenia’ myself, Moustakas (1990) notes that an autobiographical connection may involve ‘a comparable or

¹ The use of inverted commas around ‘schizophrenia’ indicates that this study is aligned with a critical view that holds the medical concept of the term in contention (cf. Bentall 2006, Boyle 2002, Read *et al* 2004, Romme *et al* 2009).

² Because the resultant film, *There is a Fault in Reality* (Cotton 2010), is an important reference point for this study a DVD of the film has been included as an additional material to the appendix.

³ The first person is used throughout this research. While Moustakas (1981, 1990, 1994) does not stipulate whether the third or first person should be used in the presentation of heuristic research, the former is often seen as more scientific. However, this seems both at odds with the ethos of the autobiographical connection required here, and disingenuous to be at once researching from a subjective, personal perspective, while attempting to appear objectively detached. For this reason, this research is presented in the first person. A more detailed rationale can be found in Chapter 4.

equivalent experience... if not the experience as such' (p14). This personal 'quest' for knowledge (p39) which underlies this study arose then from a call 'from within' the researcher's 'life experience' (p13), and involved a question that had been 'a personal challenge and puzzlement in the search to understand one's self and the world in which one lives' (p15).

One preoccupying theme throughout this quest has been the gap between the professional's *explanation* of 'mental illness' and the patient's *lived experience* of what might be more appropriately termed 'human suffering' (once moved away from a 'medical dimension' and back into the 'moral and political' dimension in which it belongs [Rapley *et al* 2011:5]). This gap exists not just in terms of how to understand what is experienced but, more importantly, how to survive it, how to make sense of it, and how to benefit from what has been learned. To draw on a metaphor that arose from the creative synthesis of the findings detailed in Chapter 6, this gap is akin to claiming only the knowledge of geologists can be valid for understanding a physical environment and its related ecosystems. In such a rendering, knowledge about life in the deep oceans or the streets of London, for example, would seem extremely limited. Drawing on the empirical research of Romme & Escher (1993), as well as his own experience of facilitating a Hearing Voices Network group (HVN), McLaughlin (2000) argues that the divergence of knowledge in this gap is now so wide that 'the dominance of psychiatric and psychological discourse is not legitimate' in the area of 'schizophrenia' (p11). This raises important questions about knowledge and power in treatment, and those with lived experience have written persuasively about this (cf. Coleman 2000; Romme *et al* 2009).

While this challenge to mental health orthodoxy is explored to some degree here, the epistemological aim of this study, which was to deconstruct the knowledge structures underpinning the diagnosis, together with what emerged in the empirical findings, steered the focus of the study toward the significance of meaning. As a result, the gap between discourses became, what was eventually conceived as, the gap between the ‘personal meaning’ of the experiencing person and the ‘medical meaning’ that is used by professionals to explain this experience. Because these terms are referred to throughout this study a brief examination is required before coming to an overview of the research approach used here in section 1.3.

1.2. ‘Personal meaning’ and ‘medical meaning’ of ‘schizophrenia’

‘Meaning’, of course, *means* many things, but for the purpose of this study, the existential-phenomenological position on meaning described in Heidegger’s *Being and Time* (2008 [1926]) is used. For Heidegger (2008), ‘Being-in-the-world’ is the primary concern when examining human experience, above any materialistic observations about individuals as ‘person-Things’ (p155). This latter ‘present-at-hand’ view of objects tells us less about our *experience* of the world than a ‘ready-at-hand’ view where meaning is derived from *the way in which we use* those objects (*ibid.*). Gelven (1989), who provides a useful guide to Heidegger’s text, notes this ‘ready-at-hand’ view turns the objective scientific view of ‘people-things’ on its head, because within it:

We do not first ask what a man is and then wonder what it means; rather we begin by asking what it means to be a man, and then we can decide what a man is (p10).

In this sense, ‘the way in which I make use of the world is meaningful’, and because of this, meaning ‘is a mode of Being here in the world’ (Gelven 1989:98). Writing from a Critical Psychiatry perspective that draws on this Heideggarian view, Bracken (2002) argues that this primacy of meaning lies at the core of the uniquely human capacity for ‘self-interpreting’ (p98). ‘Personal meaning’, then, could be said to be intimately bound up with one’s *personal* experience of Being-in-the-world. To adapt Gelven’s (1989) example, the latch to one person’s front door may be the lock to another person’s prison. On this understanding, the voices that one person hears may mean something entirely different to another. As Romme *et al*’s *Living with Voices: 50 Stories of Recovery* (2009) illustrates, those who have recovered from ‘schizophrenia’ tend to conceptualise voices as being on a continuum with thought, and regard the content of both their thoughts *and* their voices as meaningful expressions of traumatic life experience; a relationship that is supported by a growing body of research (Read & Bentall 2012). This personal ‘struggle with meaning’ (Bracken 2002:2), then, and the traumatic experiences that may underlie it, highlights the first aspect of the titular crisis.

To suggest, then, that either the voices one hears, or the thoughts one has, have a universal, non-personal meaning would be problematic. However, it is precisely this assumption of universalised meaning with which *The Diagnostic and Statistical Manual of Mental Disorders* (DSM)⁴ starts. This text, which is used to define medical meaning here, is grounded in a ‘medicine of the tissues’ epistemology (Bracken *et al* 2012:430), in which it is assumed that voices and other ‘symptoms’ of ‘schizophrenia’ are the meaningless signs of a ‘disease process’. It is argued that this

⁴ DSM-IVTR (APA 2005) is referenced in this study. DSM-V was published in May 2013, although little has changed in regard to the section on ‘Schizophrenia and Other Psychotic Disorders’ (APA 2005:297-343). While the World Health Organisation’s ICD-10 Classification of Mental and Behavioural Disorders (WHO 1992) is another key medical meaning text, DSM is the better known reference point.

objective way of looking at ‘schizophrenic’ experience leads one ‘further away’ from the ‘proper’ ontological meaning (Gelven 1989:95) of the experiencing person because the context of their use of their world has been excised. This leaves ‘the medical story’ (McCarthy-Jones 2012:316) with a fundamental dilemma in attempting to ‘know’ something about the problems it attempts to treat. Moreover, far from being objective, it is argued that DSM is as much a subjective meaning structure as personal meaning. These conflicts in the structures of knowledge underpinning medical meaning highlight the second aspect of the titular crisis.

These issues have important implications for the way ‘schizophrenia’ is understood, researched and treated, as Jacqui Dillon, Chair of HVN England (and a key source in Chapters 2 and 7), illustrates. After being hospitalised, Jacqui told her psychiatrist that the terrifying visions she was experiencing were connected to being sexually abused as a child. After listening patiently, her psychiatrist explained that what she was in fact experiencing were the ‘symptoms’ of ‘schizophrenia’. This was because:

What I was experiencing was never considered to be a natural and human response to things that had happened in my life (Dillon 2009:190).

McCarthy-Jones (2012) suggests that one way around this kind of treatment impasse might be to help those diagnosed ‘learn about their own meaning of their experiences’, rather than subjecting them to a colonisation of meaning by the ‘medical story’ – a dynamic that he likens to the imbalance of power in race, gender and imperialism (p316). Dillon & May (2002) and Coleman (2000), all ‘voice hearers’, activists and educators, endorse this reclamation of meaning from the medical complex. Yet, as Dillon (2009) reminds us, regarding voices as meaningful is loaded:

The fact that I listened to my voices was evidence of my illness, and wanting to keep them in order to understand more about myself was seen as me being resistant to treatment (p190).

In these two brief extracts from Dillon (2009) we see that *how* one understands another's personal meaning, *or not*, has important consequences for treatment, and participants in this study provided startling insights into this meaning dynamic, as this extract illustrates:

(G:51:1) [I]t was [seen as] this arbitrary symptom of mental illness... a piece of biological bad luck to be endured, rather than a complex, or significant, or meaningful experience to be explored. (G:52:1) [I]t was the beginning of this horrendous... cycle of exhaustion and hopelessness and loss of self-respect that just drains you into this shadow of yourself. (G:42:4) I think I went in [to hospital] a sort of distressed, unhappy teenager, and I came out a schizophrenic.

The treatment framework in which the crises of personal and medical meanings collide, then, creates the third and final aspect of the titular crisis.

The epistemological foundations of these three aspects of meaning crisis are explored in Chapter 3, and then discussed in light of the findings in Chapter 7, which leads to an argument that can be summarised as follows. Meaning seems to play a central role in 'schizophrenic' breakdown and recovery⁵. Crucially, how meaning is *treated* in treatment might lead to very different outcomes. On the one hand, medical meaning treatment seems governed by a mode of care that Heidegger calls *Einspringen*

⁵ What is meant by recovery is acknowledged to be varied and individual. However, because the HVN recovery discourse was prevalent amongst participants in this study, this definition seems most appropriate. In this definition recovery is seen as voice-hearers recognising 'the relationship between their voices and their emotions and what has happened to them', which results in 'the person becoming more powerful and independent' (Romme 2009:8).

Fursorge, which Boss (1963) translates into a treatment context as ‘intervening care’ (p73). Because this form of care ‘leaps in and dominates’ (Heidegger 2008:159) another’s personal meaning, it is argued that a person’s capacity for authentic self-ownership and meaning-making may be colonised, which might encourage an inauthentic “non-self-mode” (Gelven 1989:73) to develop. In so doing, medical meaning intervening care risks facilitating the passage from breakdown, or a ‘prodromal’ phase of ‘schizophrenia’ (APA 2005:302), to a long-term ‘broken self’ (Bollas 2013), or an ‘acute’ phase (APA 2005:307) of ‘schizophrenia’.

By contrast, it is argued that the form of care that Heidegger refers to as *Vorspringende Fursorge*, or ‘anticipating care’ (Boss 1963:73), might facilitate a recovery of personal meaning because it helps ‘the Other to become transparent to himself *in* his care and to become *free* for it’ (Heidegger 2008:159). This recovery of meaningful selfhood might then play a crucial role in recovery from ‘schizophrenia’ as a whole. This argument has implications for the mainstream treatment of ‘schizophrenia’, which seems dominated by medical meaning intervening care. These concepts of care go to the heart of Heidegger’s position on understanding, possibility and meaning, and are explored in more depth in Chapters 3 and 7.

Before we turn to an overview of how an understanding of the personal meanings of the participants was attempted, an immediate problem is the definition given here to the word ‘schizophrenia’. A generation before Bentall’s (2006) critical argument that ‘schizophrenia’ is ‘scientifically meaningless, clinically unhelpful and ultimately has been damaging to patients’ (p1), psychiatrist RD Laing raised similar concerns, and

stated his discomfort at using the term at all (Laing 1976 [1969]:39). By way of solution, he proposed:

Schizophrenia is the name for a condition that most psychiatrists ascribe to patients they call schizophrenic (p40).

While polemical aspects of Laing's work (which this mischievous tautology hints at) may have contributed to his marginalisation as a force in psychology, this definition signals his commitment to holding the concept of 'schizophrenia' open – in his earlier thinking at least⁶. The inverted commas around 'schizophrenia' used here reflects this held open position, and they are extended to other medical terms, such as 'symptoms'. As well as providing a held-open way of approaching 'schizophrenia', Laing provides a psychotherapeutic discourse that is grounded in Heidegger's philosophy, with which he showed that the 'psychoses [were] meaningful' (Bentall 2005:227) when experiencing persons were helped to 'articulate' their world and their 'way of being in it' (Laing 1965:25).

1.3. 'Explaining' and 'understanding' approaches to another's experience

Citing Hornstein (2009), McCarthy-Jones (2012) urges that in order to understand the meanings that voice hearers give to their experiences, we need their own 'expert accounts' as 'native speakers' and 'not just brain scans' (p315). This positioning of expertise, and the attempt to understand meaning rather than to explain substances, reflects the empirical aim of this study. Now a clinical psychologist, Lauveng (2012) - a key source along with Dillon (2009, 2012) in Chapters 2 and 7 - spent much of her

⁶ This earlier stage, referred to as Laing's 'early work' in Chapter 3, comprises aspects of Laing (1965) and (1967). At this stage Laing used the Kleinian term 'schizoid' (Mitchell 1986) to describe 'schizophrenic' experience in a general sense. In later stages of his work, Laing became notoriously caught up in attempting to define 'schizophrenia' along more polemic lines, and so closed this openness down. While Laing (1976) might be thought of as belonging to this later phase, the quote used above seems to encapsulate something of the ethos of his 'early work'.

adolescence hospitalised after a ‘schizophrenic’ breakdown. Reflecting on the terrified, wanting human being submerged beneath behaviours that others thought were inexplicable, and therefore seemingly ‘mad’, Lauveng (2012) urges that one should always remember:

Just because you don’t understand something doesn’t mean it is not understandable. It just means that you have to work a little harder to grasp the meaning (p112).

This ethos reminds us as researchers and clinicians where the responsibility for understanding must lie. Finnish psychiatrist, Yrjö Alanen (2009), argues that an ‘understanding’ approach to experiences of ‘schizophrenia’ should be the core component of treatment, rather than the dominant ‘explaining’ medical approach. A starting point for this understanding approach should be psychotherapists’ ‘ability to access their own unconscious “psychotic domain”’ (p6). Heuristic methodology, in which ‘self-awareness, and a valuing of one’s own experiences’ (Moustakas 1990:13) play an important part, was used as a way of operationalizing this approach. Polanyi’s (1969, 2009) philosophy of science lies at the heart of this methodology, and like Heidegger and Laing, Polanyi (2009) cautions that a ‘strictly detached’ objective view of human experience, in which ‘all personal elements of knowledge’ are removed, is ‘fundamentally misleading’ (p20). Similarly, the excision of a person’s ‘phenomenal world... and the meanings that they attach to their activities’ is likely to lead to absurd conclusions (p26). As such, Polanyi and Moustakas provided a methodology in which my own experiences were used to further the empirical aim of this study. Heidegger and Laing, meanwhile, provided a philosophical and psychotherapeutic framework with which to pursue the epistemological aim of this study, whilst also aiding me in the

attempt to resist explanation when attempting to understand another's 'world' and their 'way of being in it'.

1.4. Chapter overview

The literature detailing the psychotherapeutic experiences of those with the diagnosis is reviewed in **Chapter 2**. Of the 990 texts searched, only 18 yielded detail about the phenomenon, whilst retaining the essence of the person in the experience (Moustakas 1990:39). However, no comparable heuristic studies were identified. 17 texts found psychotherapy to be helpful for those with the diagnosis (the exception was the three anonymous 'service user' accounts detailed in NICE 2010). For Leszcz *et al* (1985), Dorman & Penney (1999), D'Ombraine Hewitt (2012), Mohelsky (1994), O'Brien (1960), Dillon (2012) and Lauveng (2012) psychotherapy seemed to be central to the process of recovery from 'schizophrenia'. For the last five, developing personal meaning seemed to be an important aspect of recovery, and the psychotherapy they experienced seemed to facilitate this. However, only the last three gave some detail of the *process* of psychotherapy. The chapter concludes by speculating that the dominance of medical meaning might be one key reason for this deficiency, because little value is placed on knowledge derived from the experiencing person's meaning.

Chapter 3 goes on to examine the knowledge situation that these meanings are grounded in. This begins with an overview of a modernist approach to objective knowledge on which medical meaning is grounded. Heidegger's existential-phenomenology is used both to create a framework with which one might understand another's personal meaning and to critique objective knowledge. This critique is used along with the critical clinical arguments that have been influenced by it to deconstruct

medical meaning in detail. Heidegger's interlocking concepts of understanding, possibility, meaning and care, help us to then grasp the implications of 'intervening' and 'anticipating' modes of care for another. In the final part of the chapter Laing's psychotherapeutic discourse is used to explore the implications of these arguments for the way 'schizophrenia' is researched and treated.

With the lack of data⁷ detailing the phenomenon established, along with the knowledge situation that may account for it, **Chapter 4** goes on to explore the methodological issues encountered in carrying this study out. The chapter begins by tracing the origins of the study to a previous piece of research (Cotton 2008) and the creative film process (Cotton 2010) that was carried out in tandem with this study. The ethical and methodological issues that arose from these processes informed the rationale for the qualitative approach to research used here, and the search for a suitable methodology. Potter & Wetherall's (1987) Discourse Analysis method was initially selected, but rejected for a number of reasons, which are described in some detail because they influenced the selection of Moustakas' (1990) heuristic method. The second half of the chapter describes heuristic methodology, its grounding in Polanyi's approach to personal knowledge, and the key influences of Gendlin (1962), Rogers (2004 [1961]) and Steinbeck & Ricketts (1941).

Having detailed the genesis of the study and the search for a suitable methodology, **Chapter 5** describes the method that was used to carry out the research. The chapter begins with an overview of how the 'six phases' of heuristic research (Moustakas 1990:27-32) were used and this is followed by a description of how participants were

⁷ McLeod (2003) notes that the term 'data' derives from objective psychology, and as such, the term can be problematic for psychotherapy and counselling research (p138). However, Moustakas (1990) uses this term, and so for the sake of consistency it is used here as well.

selected. To further the empirical aim of the study, a small sample of eight participants was sought in order to provide a rich quality of detail about the phenomenon. The final eight participants all had a ‘schizophrenia’ diagnosis and experience of psychotherapies across the modality spectrum. The next section describes how data was collected through open-ended, conversational interviews (Moustakas 1990:47), which were structured around a single question: ‘What are your psychotherapeutic experiences?’ ‘Self-disclosure’ was seen as one way of ‘facilitating disclosure from others’ (p17), and the personal knowledge gained from the researcher’s own experiences was a key intuitive guide to asking questions that might illuminate the phenomenon. Ethical issues are discussed in each relevant section.

Chapter 6 begins with a description of how the eight ‘Procedures for Analysis of Data’ (Moustakas 1990:51-52) were carried out. This section is illustrated with examples so the reader can follow how the process led to each component of the findings. What emerged from this analysis was a multi-perspective narrative of ‘schizophrenic’ breakdown⁸, the life experiences that contributed to it, treatment given, and finally, recovery. This chronology is preserved in the composite depiction of the phenomenon (p52), which forms the main body of the findings. This is broken down into the following five thematic groupings: **TG i) Life experience and breakdown, TG ii) Inpatient and residential treatment, TG iii) Psychotherapy that was unhelpful, TG iv) Psychotherapy that was helpful, and TG v) Recovery. TG iii), TG iv) and TGv)** are all illustrated in more detail with extracts from individual depictions and exemplary portraits (pp51-51). The aim is to give the reader a comprehensive picture of the group experience, which can be cross-referenced with complete individual

⁸ Some participants referred to this term directly, others referred to a stage where they were no longer able to function. For some, breakdown seemed a slow, drawn out process, while for others there was a specific moment that they were able to pinpoint.

depictions and two exemplary portraits for each person in the group, which can be found in the appendix.

The composite depiction shows that psychotherapy was considered a core facilitator of recovery. However, aspects of psychotherapy were also unhelpful. The key delineating aspect seemed to be how personal meaning was either facilitated, or inhibited. In general, it was found that all participants regarded their ‘symptoms’ as a meaningful expression of earlier traumatic experiences, and that once this meaning was addressed, both through helpful aspects of psychotherapy and other facilitators of personal meaning, such as HVN, ‘symptoms’ seemed to be more effectively reduced than by the attempt to control them medically. At the end of the chapter, the findings are summarised in a creative synthesis, where ‘[t]he researcher as scientist-artist develops an aesthetic rendition of the themes and essential meanings of the phenomenon’ (Moustakas 1990:52). A metaphorical narrative form is used, in which the participants’ embodied experiences are likened to an environmental system.

The discussion in **Chapter 7** takes place in three parts. In the first two, the empirical findings are discussed in relation to the findings from the literature reviewed in Chapter 2, and the epistemological arguments raised in Chapter 3. The helpful aspects of psychotherapy (7.2.1.) that facilitated personal meaning are concluded to share qualities with anticipating care, whereas unhelpful qualities of psychotherapy – and treatment as a whole (7.2.2.) – are likened to intervening care. In the third part (7.2.3.), this conclusion is widened into to an argument in which it is speculated that medical meaning intervening care might obstruct recovery by dominating a person’s ability to resolve their crisis of personal meaning. In turn, the passage from breakdown, or a ‘prodromal’

phase of ‘schizophrenia’ (APA 2005:302), to ‘broken self’ (Bollas 2013), or ‘acute’ phase of ‘schizophrenia’ (APA 2005:307), may be unwittingly facilitated.

Section 7.3. then explores the implications of this research for clinical practice, and it is argued that NICE guidelines (NCCMH 2010) seem to embrace the same medical meaning intervening care values that were argued to be unhelpful. A brief exploration of forms of psychotherapy that might embrace an anticipating care approach follows, which concludes with a six-point distillation of what aspects of psychotherapy were found helpful in this study. The implications of the research both for myself as a person *and* researcher follow in section 7.4. As well as facilitating an ‘understanding’ approach to other people’s experiences, one key outcome was learning more about my own experiences, and how to speak about them. In the final part of the chapter, there is a critical evaluation of the study (7.5.). This is followed by suggestions for further research 7.6.).

The chapter concludes (7.7.) with a brief summary of arguments, and it is speculated that wider economic and cultural forces within science might support the current mainstream treatment *status quo*, despite scientific contradictions and poor outcomes. The environmental metaphor used in the creative synthesis is likened to *Dasein*’s ‘special environmental Being’ (Heidegger 2008:160). This is briefly argued to provide the basis for a ‘mind environmentalism’, which might challenge this *status quo*, just as the environmental movement has challenged the dominant modernist approach to man’s interaction with nature.

Chapter 2

Review of literature detailing the psychotherapeutic experiences of those with a ‘schizophrenia’ diagnosis

2.1 Introduction

This chapter reviews literature detailing the psychotherapeutic experiences of those with a ‘schizophrenia’ diagnosis. In recent years peer support networks, such as HVN, have popularised the term ‘expert by experience’ (Watkins 2008), and contributed to a growing recovery movement (Romme *et al* 2009). This reflects a broader cultural shift in which those with lived experience are often now included on advisory and guideline development panels, such as NICE (NCCMH 2010). Why should this perspective matter? Sommer (2003) points out that first person narratives are a valuable resource for others attempting to negotiate their way through recovery. Geekie *et al* (2012) suggest that such narratives are recognised as an important source of knowledge about ‘schizophrenia’ and its treatment. Read & Bentall’s (2012) meta-analysis of studies researching the link between traumatic life experience and ‘psychosis’, meanwhile, suggests why such knowledge is important⁹. Yet Chadwick (2009) notes, experiences of people diagnosed with ‘schizophrenia’ are still not well represented, and this seems born out by the limited amount of texts found relating to the phenomenon researched here.

While a number of relevant qualitative studies were identified (for example, Stanton & David 2000; Coursey *et al* 1995; Boll 1999; Leszcz *et al* 1985; Masoni *et al* 2000), little detail was provided in a way where ‘the essence of the person in the experience’ (Moustakas 1990:39) was retained. The most useful texts reviewed in section 2.4. were first person accounts, however, of these only Dillon (2012), Lauveng (2012) and O’Brien (1960) gave any degree of detail about *what* was experienced in psychotherapy. There were no comparable heuristic studies, in which the self of the researcher was used as a way of exploring the phenomenon.

⁹ This link is explored in Chapter 3, and then in greater depth in light of the findings in Chapter 7.

The chapter closes (2.5.) with a summary of four factors that might account for the lack of relevant literature. The first three factors relate to the primacy given to medical meaning in research into, and treatment of, ‘schizophrenia’. This meaning and the modernist structures of knowledge in which it is grounded are examined in the next chapter, along with phenomenological and critical discourses that question its suitability for understanding human experience in this area.

2.2. Definitions

‘Psychotherapy’ is used as a generic term to represent all talking treatments including clinical psychology and its affiliates, such as CBT and DBT; counselling; psychotherapy, including all of the differing modalities contained within this term, such as psychoanalysis; and psychiatry, where there is a talking therapy aspect to the treatment.

‘Schizophrenia’ is used as an umbrella term to represent ‘Schizophrenia’¹⁰ and its subtypes, ‘Paranoid, Hebephrenic, Catatonic, Undifferentiated, or Residual’ (APA 2005), as well as Schizoaffective Disorder, and Schizophreniform disorder (*ibid.*)¹¹.

2.3. Literature search

The search focused on studies with a comparable empirical aim of exploring the psychotherapeutic experiences of those with a ‘schizophrenia’ diagnosis. While there were thousands of texts measuring psychotherapy outcomes for those with the diagnosis,

¹⁰ When capitalised as a proper noun Schizophrenia refers to the specific diagnosis (APA 2005:298-397) as opposed to the umbrella medical meaning concept of ‘schizophrenia’.

¹¹ The structure of the diagnosis is explored in more detail in Chapters 3 and 7.

the challenge was to find literature that detailed experiences of the phenomenon from the perspective of the experiencing person, and the meanings they drew from this.

The following databases were searched: PsychINFO, PsychARTICLES, PsychBOOKS, Academic Search Premier, and Education Research Complete. The search years 1927 – 2012 were used.

The first search term used was: ‘schizophrenia’ AND ‘experiences’ AND ‘psychotherapy’. This yielded 924 texts. However, the experience represented was often that of the professional treating those with the diagnosis, or the perspective of their families. Where the experience of those with the diagnosis was the focus, the individual became lost in reduction.

The following refined search term concentrated on first person accounts of the phenomenon: ‘schizophrenia’ AND ‘first person account’ AND ‘psychotherapy’. This yielded 18 texts. A third search term: ‘schizophrenia’ AND ‘autobiographical’ AND ‘psychotherapy’, yielded 13 texts. A fourth search term: ‘schizophrenia’ AND ‘first person experience’ AND ‘psychotherapy’ yielded 35 texts. These last three searches generally yielded texts that had been found in the first search.

Of the 990 texts searched, only 18 contained first person accounts of experiences of psychotherapy by those with the diagnosis. There were a small number of additional texts that were discounted because the first person accounts were geared toward providing data for RCTs. These texts were less relevant, because the individual had been

lost. A further 5 texts featuring first person accounts were sourced in the process of conducting this study.

2.4. Literature review

We will start with first person accounts, which provided the most detail about the phenomenon from the perspective of the experiencing person. Co-authored accounts follow this, and then finally studies that researched experiences relevant to the phenomenon.

First person accounts

O'Brien (1960) contains a detailed account of the authors' experiences of 'schizophrenia'. For 6 months she was swept up by a 'delusion' populated by sinister 'Operators' who ruled her life and sent her on a labyrinthine mission crisscrossing America in Greyhound buses. Her mission brought her to a psychoanalyst's consulting room in which she began to confront some of the painful life experiences that she now believed were being acted out on a 'psychotic' stage.

Insanity was for me, a training programme, accompanied by escape from actual stress until I could gain what I needed psychologically to face the same stress in actuality (p150).

The author has many insights about how she came to understand her 'psychotic symptoms' as metaphors for unresolved life experiences. However, while she felt strongly that psychotherapy marked the start of recovery (p126), little detail of *what* actually took place is offered beyond general observations. For example, she found that 'to a psychiatrist the unconscious mind, is insanity, is a machine out of working

order, no more, no less’, whereas her psychoanalyst valued the content of her unconscious ‘as an instrument, in his treatment of me...’ (p125).

Geekie *et al*’s (2012) *Experiencing Psychosis* provides a valuable source of first hand accounts of ‘schizophrenia’. Jacqui Dillon, Chair of HVN England, and participant in Cotton (2010), gives a particularly strong account that also refers to her experience of psychotherapy. For her, psychotherapy offered an alternative to the psychiatric medical model, and this was the first time she felt her experiences were ‘believed’, rather than being told that she lacked ‘insight’ into her ‘biological illness’ (Dillon 2012:18). Dillon found that the ‘therapeutic alliance’ she formed with a number of therapists over several years was ‘the key thing that enabled me to transform my subjective reality of a terrifying internal and external world’ (p19). In this process, developing her own meaning of her ‘symptoms’ helped her understand how they related to the sexual abuse she had suffered as a child. In so doing, her feelings toward her voices changed from terror to compassion and acceptance (pp19-20).

For Chadwick (2006, 2009), a psychologist who writes about his own experiences of ‘schizophrenia’, ‘well targeted medication revolutionised my life’. This enabled him to take part in gestalt and encounter groups, where he gained a greater degree of access to his feelings. In turn, this helped enhance his cognitive function and integrate thought and feeling – ‘something conservatively minded scientists probably would not expect’ (Chadwick 2009:53). Later in his recovery, he worked with a psychoanalyst. While he felt that this was initially too challenging ‘and often prompted the need to take extra medication to reduce stress and arousal’ (Chadwick 2009:58), he found that combined

with medication, this approach led to a reduction in anxiety, which had the effect of reducing paranoid ideas and increased his feelings of happiness (p59).

Mohelsky (1994), now a psychiatrist, describes being in psychoanalysis as an integral part of his recovery. Unlike Chadwick, Mohelsky found the ‘whack on the head’ he experienced in the early stages of psychoanalysis positive and enriching, and he credits it with helping him gain a greater understanding of his ‘psychotic’ experiences. However, while his paper is rich in detail about the outcome of this meaning-making process, there is no detail about the psychotherapy process itself.

The Schizophrenia Bulletin features three accounts of ‘schizophrenia’ that also detail experiences of psychotherapy (Anon1 1989, Anon2 1990, Wagner 1996). Like Chadwick, all three also found a combination of psychotherapy and psychiatric medication an important part of their recovery; however, there is little detail available.

NICE Guidelines for Schizophrenia (NCCMH 2010) features three accounts, in which a combination of medication and supportive relationships, such as social workers and CPNs, helped with stability. However, the descriptions of the experiences of psychotherapy are brief. ‘Personal Account A’ mentions a desire to come off medication and working with his CPN in an undisclosed therapeutic modality, but, there is no further detail, other than it was not useful (p52). ‘B’ states that after many years of being a revolving door patient, he now works with a counsellor who assists him ‘to be the best I can, through the ups and downs’ (p54). ‘C’ began training as a counsellor, but did not complete and now works as an educator and researcher in mental health. ‘C’ tried CBT but found it a ‘struggle’ to keep a written record when ‘ill’ (p56).

Lauveng's (2012) autobiography, *A Road Back from Schizophrenia*, yielded the most detail of all of the first person texts. Similar to O'Brien (1960), Lauveng regards 'psychosis' as a pressure valve that allowed her distance from an underlying painful reality – in this case, compounded by the death of her father. Lauveng's (2012) text contains detailed experiences of long-term psychiatric inpatient treatment, as well as detailed experiences of psychotherapy, with the added perspective of her current practice as a clinical psychologist. This twin perspective seems to have enabled her to explore the meaning of her 'schizophrenic' experiences in depth, as well as giving her a conceptual framework with which to deconstruct the treatment she received, as this extract concerning the embodied subjectivity of human beings exemplifies:

Diagnosis means categorizing *humans*, and that will always be different from categorizing objects... Humans *know what is going on* and they are affected by it for better or for worse (p115).

Lauveng (2012) seems to link medical treatment with a deepening of the internal split she felt between painful feelings and the abstracted, metaphorical 'psychotic' entities she believed expressed them. This internal fracture led to a feeling that she was no longer an "I", more a depersonalised "she" that had no centre. By contrast, the psychotherapy she experienced over the years (with several therapists) seemed integral to her recovery. For her, the most important qualities were her therapists' kindness and interest in her, their patience to stay with her for years - even when it felt like little progress was being made - daring to be honest, to hope when it seemed there was none, and their ability to experience pain, but without becoming defensive or defeated by it. However, the quality most frequently referred to was the opportunity to 'explore the connections between my symptoms and my life' (p56). She considered one long-term therapist a 'travel

companion who listened so well’ that *she* began listening too because ‘it was suddenly allowed and even encouraged’. In listening, she began to hear what her ‘symptoms’ were saying, and this allowed her to understand their meaning, which seemed the key to her recovery.

Lauveng (2012) contrasts this meaning-making process with the medical attempt to explain and control, rather than understand her ‘symptoms’, and which saw little value in encouraging an exploring, listening process in which this meaning could be discovered. This analysis helped to crystallise my own understanding of what emerged in the findings of this study, and played an important role in the argument developed in Chapter 7. For this reason, Lauveng (2012), as well as two of the other most useful texts (O’Brien 1960 and Dillon 2012), are the texts from the literature search that are most frequently revisited in Chapter 7.

Co-authored accounts

Mary Barnes: Two Accounts of a Journey Through Madness (Barnes & Berke 1974), describes the experiences of Mary Barnes, a resident in Laing’s experimental residential therapeutic community, Kingsley Hall – the focus of Cotton (2008), and Cotton & Loewenthal (2011). The book describes Barne’s close therapeutic relationship with Joe Berke, an American psychiatrist who became part of the community. Told from both their perspectives, it is clear the relationship was healing for Mary, and was an important part of her recovery. However, while Barnes writes at length about her inner journey, this is often difficult to relate to what may, or may not, have been happening therapeutically in the relationship itself, and what detail there is

in this regard is mostly supplied from Berke's perspective. Moreover, in the Kingsley Hall discourse, Mary and Berke's therapeutic relationship was a 'non-therapy', inseparable from the 'non-treatment' ideal embodied in the wider milieu of the community itself. Berke mentions that formal psychotherapy sessions did occur outside the community (p251). However, it is difficult to get a sense of what this experience actually comprised. Perhaps one could summarise that while the relationship was not referred to as 'psychotherapy', it did seem to be *therapeutic* and helpful.

Dorman & Penney (1999) speak more explicitly about this relationship from the perspective of both psychotherapist and client. Penney summarises her experience in a poem, in which she attributes a process of healing, re-awakening, and an emergence from the nightmare of 'catatonic symptoms and continuous auditory hallucinations' to the psychotherapy (p11). However, detail is sparse. In a similar vein, Levander & Werbart (2003) designed a research project where 'two psychotic patients and their therapists were asked to describe the patient's problem, its background and preferential treatment' (p163). While the study provides some useful material concerning what both believed the process of the psychotherapy to be, it is focussed on the generation of personal theory in relation to 'symptoms' and on the level of concordance, or dissonance between the accounts.

Case study

Stoller (1997) provides a detailed account of his psychoanalytic work with Mrs G, a young woman with the diagnosis, who believed she had a penis growing inside her. While told only from the therapist's perspective, and so less relevant here, the text is

mentioned because of the astonishing depth of detail about the process of the work and Stoller's experience of the therapeutic relationship.

Studies researching experiences of 'schizophrenia' and psychotherapy

Stanton & David (2000) reviewed 29 autobiographical accounts of 'schizophrenia', and, like Chadwick, found most attributed their recovery to a combination of medication, psychotherapy, social support, and coping strategies. Coursey *et al* (1995) researched the experiences of 191 participants with 'serious mental illness' who had also experienced psychotherapy, and found that 25% felt psychotherapy was the most helpful 'intervention', as opposed to 16% who thought medication was the most beneficial. 60% overall thought a combination of the two was the most helpful. 84% of participants with a 'schizophrenia' diagnosis 'preferred brief, less frequent sessions of reality-oriented therapy over longer, more frequent sessions of insight therapy' (p283). However, as the presentation of data suggests, the study has a quantitative framework which is less concerned with the phenomenological 'essence of the experience' (Moustakas 1990:39) sought here.

Boll (1999) researched the experiences of those with a 'schizophrenia' diagnosis who took part in short-term integrative group psychotherapy. Like Chadwick, participants found expressing problems on an emotional level (rather than explicitly addressing 'psychotic symptoms') led to a reduction in levels of stress, and provided a safe arena for 'reality testing' (p50). Participants believed access to the group in the longer term would have been helpful, if made available.

Leszcz *et al* (1985) conducted interviews with inpatients on discharge, and found group psychotherapy was ‘a highly valued component of the overall inpatient treatment’ (p411). Masoni *et al* (2000), meanwhile, describe how the six participants in their study with ‘schizophrenia’ or ‘schizotypal’ diagnoses found that a psychodynamic group intervention program where they were able to develop free verbal communication, led to ‘a positive loosening of chronic states, reanimation of psychic life, adoption of new modes of interpersonal relationships, and more developed thinking patterns’ (p93).

D’Ombraine Hewitt (2012) investigated the therapeutic relationship with eight women between the ages of forty-two and sixty. All had diagnoses of Schizophrenia and Schizoaffective Disorder and spoke about their experiences of person-centred psychotherapy. Core helping aspects of the relationship were found to be trust, feeling the therapist was interested in them, working collaboratively, and facilitating a ‘changed/reclaimed sense of self’, and overall the psychotherapy was felt to be a ‘life-changing experience’ (pp30-33). CBT is noted as dominating the psychological treatment of ‘schizophrenia’, and it is suggested that while approaches such as person-centred therapy may not be as well evidence based, they appear no less effective.

Finally, Barker *et al* (1999) depict a range of patients’ experiences of psychotherapy, as well as other mental health services, such as social work, psychiatry and nursing. However, the participants are drawn from a population with a range of ‘psychotic disorders’, including bipolar disorder, which is not the focus of this study.

Overall however, none of the studies reviewed in this section offered detail about the phenomenon from the perspective of the experiencing person, or the meanings they attributed to the process of psychotherapy itself.

2.5 Conclusion

The texts searched indicate psychotherapy was helpful, if not central to recovery. The exception was ('C') (NCCMH 2010). Several texts concluded that psychotherapy was most beneficial when combined with medication (Chadwick 2009, Coursey *et al* 1995), or medication and social support together (Anon1 1989, Anon2 1990, NCCMH 2010, Stanton & David 2000 and Wagner 1996). What emerged most strongly from the experiences researched was as follows.

The quality of the therapeutic relationship (Barnes & Berke 1974, Dillon 2012, D'Ombraine Hewitt 2012, Dorman & Penny 1999, Lauveng 2012,) seemed important. Within this, the safety afforded by the relationship was also important (Boll 1999, Dillon 2012, Lauveng 2012), along with the longevity of the relationship (Dillon 2012, Lauveng 2012 and Stoller 1997) – although Coursey *et al* (1995) seemed to find the reverse. Psychotherapy providing a space to explore the meaning of 'symptoms' was another important quality (Dillon 2012, Lauveng 2012, Mohelsky 1994, O'Brien 1960, Stoller 1997). In terms of outcome, the integration of internal states, such as thoughts and feelings, seemed commonly valued (Boll 1999, Chadwick 2009, Lauveng 2012, Masoni *et al* 2000); recovering a sense of self (Dillon 2012, D'Ombraine Hewitt 2012, Lauveng 2012, O'Brien 1960); and finally, enhanced capacity for interpersonal relationships (Mason *et al* 2000).

There was little detail about what was considered unhelpful, other than ‘C’ (NCCMH 2010) finding the need to keep a written record of experiences when unwell during his CBT too challenging, and Chadwick (2009) finding psychoanalysis ‘stressful’ at times – although it was felt to eventually reduce ‘anxiety’ and increase a sense of ‘happiness’. Dillon (2012), Lauveng (2012), O’Brien (1960) appeared to find the *absence* of a ‘symptom’ focussed treatment framework allowed them freedom to explore meaning, a notion that seemed supported by Mohelsky (1994) and Stoller (1997), who also placed value on the exploration of meaning.

Overall, there seemed little detail about what was experienced in the psychotherapy process itself, and what meaning was drawn from this. For instance, *why* did participants think it was helpful or unhelpful and *what* did they understand to be happening from *their* perspective? Knowledge in this area would seem useful if one is to ‘know’ something about what is helpful, or unhelpful about psychotherapy for those with the diagnosis. When then does there seem to be such an obvious lack?

The most conspicuous reason may be the prevalence of medical meaning in mainstream research and treatment. Read *et al* (2001) found that of the 33,648 studies researching causes of ‘schizophrenia’ between 1964 and 2004, less than 1% examined the impact of parental care (p321). This research landscape comes loaded with the assumption that ‘schizophrenia’ is the meaningless product of a ‘disease’ that *produces* a breakdown of meaning, rather than what is observed at the material level *representing* a breakdown of meaning, brought about by experiences such as trauma (Bracken 2002). While NICE’s (NCCMH 2010) interpretation of ‘schizophrenia’ attempts to incorporate the possibility of ‘biological, social and psychological’ causes (p22), it is essentially rooted in medical

meaning, with the consequence that ‘the presenting issues of service users’ are assumed to be ‘of a medical nature’ (Guy *et al* 2011). In essence then, little value is placed on knowledge about patient’s personal meaning, or the role it might take in recovery, because ‘symptoms’ are considered meaning-*less* beyond being regarded as signifiers of a ‘disease process’ that needs to be ‘controlled’.

Secondly, because NICE-recommended psychotherapies are required to fit within this medical meaning framework, their efficacy is judged on ‘symptom’ management outcomes. Moreover, NICE’s concept of psychotherapy efficacy is dominated by, what Silverman (2005) calls ‘the discipline of psychology’, which downplays ‘linguistic and sociological issues’ (p115). One result of this discipline is that the Randomised Control Trials (RCTs) that NICE uses to measure efficacy have been noted to be problematic in their attempt to objectively measure subjective human experience (Loewenthal & House 2008). Accordingly, there is little interest in the detail or quality of the actual experience, or the meaning that patients attribute to it. Thirdly, as the participants in this study illustrate, because medication is seen as the primary form of treatment, psychotherapy is inconsistently offered by the NHS for those with the diagnosis. Lack of access therefore reduces the pool of experiences that can be researched. Finally, the life experiences of those with the diagnosis are often traumatic, and discussing these stories may be difficult and distressing in itself, acting as a potential disincentive to take part in research that explores such experiences in detail.

The context for the first of these points, the modernist structures of objective knowledge that are used to explain another’s experiences with medical meaning, are examined in the next chapter through the prism of phenomenological and critical discourses. It is

argued that these discourses might provide an alternative framework for understanding another's personal meaning. The second point, how these issues might play out in a research setting, is explored in Chapter 4, along with a description of how a methodology was developed for this study. The third and fourth points, which refer to the difficulty of finding participants with whom to research this experience, are examined in Chapter 4, and the method used here is described in Chapter 5.

Chapter 3

Structures of knowledge underpinning medical and personal meanings of 'schizophrenia'

3.1. Introduction

We have established that literature containing the psychotherapeutic experiences of those with the diagnosis lack detail about their personal meaning, and that the dominance of medical meaning in research and treatment may account for this lack. This chapter begins with an examination of the modernist, objective structures of knowledge that the medical meaning of DSM is grounded in (3.2.). The attempt to find a method of researching personal meaning from an understanding perspective, in which my own knowing structures could be considered, led to a deeper investigation of Heidegger's position on meaning. As well as helping to define what is meant here by personal and medical meanings, Heidegger's existential-phenomenology has been useful in two further areas, whose relevance only became clear during the course of writing the study up.

The first is Heidegger's criticism of objective knowledge and his concept of *Dasein* (3.3.), which are both used to deconstruct medical meaning in conjunction with some of the critical clinical discourses that have been influenced by Heidegger's argument (3.4.). Having established working definitions of personal and medical meanings for this study, the concept of *Dasein* leads us into a description of the interlocking concepts of understanding, possibility, meaning and care, and the implications of 'intervening' and 'anticipating' modes of care might when used in treatment (3.5.). In the final section of the chapter (3.6.), these issues are explored within the clinical framework of Laing's 'existential-analytic' (Loewenthal 2011:4) approach to 'schizophrenia'. These issues are revisited in Chapter 7 where they are discussed in light of the findings, and where Heidegger's modes of care are examined in more detail.

3.2. Modernist objective knowledge and the foundation of medical meaning

In Chapter 1 it was noted that objective meaning is ‘misleading, if not downright inaccurate’ in its attempt to explain human experience without its subjective, existential components (Gelven 1989:101). To understand the significance of Heidegger’s argument for what is researched here, we need to begin by uncovering the roots of modernist structures of knowledge, in which this separation is deemed possible.

While associated with the modern post-Enlightenment period, the foundations of modernism can be traced back to Plato [BC 427-437], whose *Theory of Forms* proposed that phenomena are material (Mautner 1996:425-9), and can be separated from the knowing subject’s experience of them. This separation can be seen in Descartes’ (1662 [1637]) nascent modernist thinking, whose formulation of *Cognito ergo sum* (‘I think, therefore I am’) positioned the knower as locked up in his individual mind, distinct from the thing to be known. A.J. Ayer, who was a leading proponent of logical positivism, an objective approach to knowledge that underpins DSM from DSM-III onwards (Kirk & Kutchins 1992:11), notes that in attempting to ground knowledge in verifiable empirical experience, Descartes believed the act of his thought alone verified his existence (Ayer 1956:45).

Gill (2000), whose *Tacit Mode* provides a useful guide to Polanyi’s work, notes that Hume’s Empiricism (Hume 1961 [1739]) - an important influence both for Ayer and for cognitive philosophy (Garret 1997) - proposed a ‘foundationalist approach to questions of epistemology’ (Gill 2000:18). This approach attempted to further Descartes’ project by beginning ‘with a rock-bottom analysis of human cognitive

experience upon which to construct the structure of knowledge' (*ibid.*). This 'Enlightenment', nascent modernist epistemology was driven by 'a desire to provide a foundation for knowledge which would make it immune to scepticism' (Mautner 1996:175). However, this attempt to arrive at immune 'either, or' conclusions required a grounding in mathematical *axioms*. This requirement leaves a narrow lens through which to view the world, because 'mathematical knowledge is essentially empty of factual truth' about it (Gill 2000:15), and includes 'only those ideas and claims that can be grounded in sensory experience and tested by empirical methods' (p4).

Kant's transcendental philosophy (1929 [1781]) attempted to move beyond Hume's position by separating the contents of experience from the structures of mind that shape cognitive activity, with the latter viewed as a locus for the possibility of the former. While this negates the 'infinite regress' of Hume's proposition (Gill 200:22), Kant's attempt to separate pure reason from the practical leads to a dichotomy between 'the experiential, phenomenal world, and the transcendent, noumenal world' (p27). The dualism of both Kant's dichotomy between the knowable and the unknowable, and Descartes' separation between mind and body (p28) have led to the 'chief epistemological dilemma of modernism': the choice between a grounding for knowledge that is immune from scepticism and 'open-ended relativism', and between objectivity and subjectivity (p29). Gill argues that this dualism has led to 'the reductionist approach to medicine' and 'the gulf between science and ethics' (p28).

Translated into the behavioural sciences House (2010) argues this modernist focus on objectivity becomes an 'anxiety-driven... impulse to measure, assess, control and

mechanise' (p236). We can see these values reflected in influential behavioural psychologists such as B.F Skinner [1904-1990] and John Watson [1878-1958], who believed that 'if it could not be counted or measured, it did not matter' (Peltier 2010:82). Similarly, Karl Popper's (1970) aim 'to eliminate entirely the personal element in knowledge' (Gill 2000:9) would seem the apogee of these modernist, objective scientific aims.

Yet, crucially, this dichotomy between subjectivity and objectivity is artificial because '[t]he mind is not the passive reflector of an external world and its intrinsic order, but is active and creative in the process of perception and cognition' (Tarnas 1996:396). In the attempt to separate this active process of perception and cognition from a desired 'objective reality', a modernist approach to knowledge about human experience is likely to be 'fundamentally misleading' (Polanyi 2009:20) because it leads to reductive, abstracted conclusions that are stripped of subjective, existential meaning – what has been inelegantly termed here, 'personal meaning'.

Ayer's (1956) logical positivist position attempts to bring the two halves of this dichotomy together again by acknowledging there is a gap between experience and observable behaviour. However, this becomes an issue of verification for him, and to solve it, he makes a case for how another's experience might become explicitly known to us through the 'dimensions of our language' and a 'wide variety of experienced instances' (p222). This seems a similar position to Kant's 'transcendental *a priori*' where 'certain structures of experience and thought' are held to 'be common to all cultures' (Clarke, C. 1996:152).

In these modernist structures of knowledge then, we glimpse a number of assumptions about how experience and the personal meaning derived from it are seen as either the *irrelevant* antecedents to observable, measurable (and therefore, *relevant*) behaviour (Skinner, Popper, Watson), or private, but *generalisable*, and therefore knowable (Kant, Ayer). We can see these modernist, objective assumptions underpinning the DSM medical meaning of ‘schizophrenia’ in section 3.4. Before we come to this, we will first examine how Heidegger provides an alternative ontological framework with which we can both define personal meaning and think about the issues that arise from the attempt to create objective knowledge about human experience. This will also help us to situate Heidegger’s critique of objectivity in a wider critical discourse in section 3.4.

3.3. Heidegger, personal meaning, and a critique of objective knowledge

Tarnas (1996) notes that in his attempt to separate subjective experiencing of the world from the world itself, ‘Kant had drawn attention to the crucial fact that all human knowledge is interpretive’ (p417), ‘unrooted’ and ‘subjective’, and in so doing became the inadvertent pivot between modernism and postmodernity (p418). One key protean postmodern strand of thought was Edmund Husserl’s [1859-1938] transcendental phenomenology (1960). Like Kant, who was sceptical of ‘substantive knowledge claims about the world’ that were independent of experience (Mautner 1996:291), Husserl sought to enquire more deeply into the ‘subjective ordering of reality’ and so provided postmodernism with a method (Loewenthal & Snell 2003:1).

Husserl’s philosophy is rooted in Aristotle’s rebuttal of Plato’s *Theory of Forms* (Fine 1992), in which Aristotle insisted that the objective aspects of phenomena are

inseparable from our *experience* of them, because this experience is a part of phenomena themselves. Because experience is subjective and individual it follows that from a phenomenological perspective, there can be no *universal* truth about human experience on which knowledge is founded, rather, many truths that lead to a postmodern ‘either, *and*’ conclusion. Burston (2000), who provides a comprehensive guide to Laing’s work, notes that phenomenology’s emphasis on “‘lived” experience... precedes the objectified and abstract world of natural-scientific inquiry’ (p77). Rather than trying to ‘explain’ the world ‘in causal or scientific terms’ then, phenomenology attempts to describe in detail what is found (*ibid.*).

However, in assuming that the experienced world can be separated from the world containing the person experiencing it, Husserl’s transcendental phenomenology encounters a similar problem to Kant in the Cartesian assumption that the transcendental ego can bracket off the existence of others, but not itself. Therefore, while Husserl rejected Descartes’ ‘dualism of mind and matter... he did not transcend it in a convincing way’ (Burston 2000:19). One way that phenomenology moved beyond this problem was with Husserl’s one-time student, Martin Heidegger [1889-1976], whose existential approach to phenomenology stressed the primacy of Being.

For Heidegger (2008), the Enlightenment ‘Interpretation of Being’ had become a dogma that ‘not only declares the question about the meaning of Being to be superfluous, but sanctions its complete neglect’ (p2). As we saw in Chapter 1, Heidegger inverts the objective knowledge situation by asking ‘what it means to be a man’ in order to ‘decide what a man is’ (Gelven 1989:10), and ‘refuses to separate’ this Being from ‘the study of man’ (p19). This ontological analysis enables one to

discover something about the world ‘as I am in it’, whereas ‘Descartes’ interpretation merely tells me *how I can think* about it’ as a world of substances (p124). This stance is key to appreciating Heidegger’s distinction between a ‘present-at-hand’ view of the world (objective, impersonal, and based on generalisable truths about substances dislocated from their use) and one that is ‘ready-at-hand’ (subjective, personal and informed by the individual’s use of the world). Because *the way* in which a person makes use of the world is ‘meaningful’, from this ready-at-hand view meaning is necessarily seen as ‘a mode of Being here in the world’ (Gelven 1989:98).

Crucially, ‘Being-in-the-world’ always involves Being-with Others because, ‘the world is always the one I share with Others. The world of Dasein is a *with-world*’ (Heidegger 2008:154). We need to examine this notion of *Dasein* more closely now because it is central to three core aspects of the argument being developed here. Firstly, it is through *Dasein* that we can appreciate how use of the world is inseparable from the inter-subjective context in which this usage occurs, and how both are central to personal meaning. Secondly, the structure of *Dasein* has important implications when ‘Others become themes for study’ (Heidegger 2008:155). Thirdly, it is through *Dasein* that we grasp the interlocking concepts of understanding, possibility, meaning and care. The first two aspects are explored in the remainder of this section, and the third is explored in section 3.5.

Craig (1988) notes that *Dasein* in its original German usage means to ‘be there; be present; exist, be in existence; be available’, and that Heidegger uses this term to ‘name human existence’ (p11). As such, *Dasein* could be seen as Heidegger’s attempt to phenomenologically describe the experience of Being-in-the-world ‘in a specific

temporal and historical context, the cultural context – *this* place and time’

(Loewenthal & Snell 2003:26). This context might then tell us something about ‘how a person’s position within the... external world influences the way they experience and think about’ it (Greenwood & Loewenthal 2011:58).

Being, then, is intrinsically inter-subjective, because one person’s *Dasein* is always in relationship with surrounding *Daseins*. Heidegger (2008) insists, therefore, that to look meaningfully at human experience, the entire *Dasein* of the individual must be taken into account in the context of their ‘environmental Being’ (p160). There is a clear implication here for both researchers and clinicians, and for ‘Others’ who become ‘themes for’ their ‘study’ (Heidegger 2008:160), because ‘the *way* in which we enquire is part of our being’ (Loewenthal & Snell 2003:26). Not only must the subject be seen in his *Dasein* in order to know something about him then, the researcher must acknowledge his own Dasein-with within the knowledge situation and how that might affect the subject. This highlights the limitations of Cartesian and Kantian approaches to knowledge, because from the perspective of *Dasein* ‘one cannot begin the analysis of the self from a naked and lonely “I”, or pure consciousness’ (Gelven 1989:70), and a similar problem is raised with ‘Husserl’s attempt to show a pure Subjectivity’ (Loewenthal 2011:10).

In summary then, personal meaning could be said to be the product of an individual’s subjective interpretation of Being in the world, which is formed by the way in which they *use* this world. Because *Dasein* involves Being-with, this usage is both particular to the *context* in which that person exists in the world, and subject to the meanings of the surrounding *Daseins*. In order to attempt to create an objective knowledge

situation the *Dasein* of both observed *and* observer (or subject/patient *and* doctor/therapist/ researcher) must be first excised. However, this is to ignore essential personal meaning and to render *both* non-human meaning-*less* ‘person-Things’ (Heidegger 2008:155) in the process, resulting in a knowledge about the person observed that is ‘*unmeaning*’ because it is ‘essentially devoid of any’ ontological ‘meaning at all’ (p193). We can see now how these arguments play out in critical clinical discourses, which together with Heidegger’s thinking help us to examine medical meaning more closely.

3.4. Medical meaning – a critical deconstruction

While Popper, Watson and Skinner characterised objective psychology in the first half of the 20th century, Heidegger’s argument, amongst others, can be seen in post-war philosophies of science. For example, Kuhn (1996) argues that science is a culturally influenced activity that is subject to paradigmatic shifts, rather than being a stand-alone edifice of ‘verifiable knowledge’. Similarly, Polanyi (2009) argues that objective science fails to grasp the significance of tacit knowledge, where we can ‘*know more than we can tell*’ (p4), and that processes, such as perception, are active rather than passive. From this perspective, knowledge – including its cultural context – ‘indwells’ tacitly within us and shapes the world we perceive. Rather than being objective then, ‘all natural sciences are loaded with assumptions and exist in social and historical contexts that determine their priorities and agendas’ (Bracken 2002:98). Parker (1999) argues that consequently, to occupy a critical position in psychology ‘does not mean finding the correct standpoint, but it means understanding how we come to stand where we are’ (p4).

One important clinical argument advanced from this critical position is that psychiatry as a whole has become dominated by a ‘positivist’ “technological paradigm”, which aspires to ‘the same epistemology as a medicine of the tissues’ (Bracken *et al* 2012:430). We can see this ‘technological paradigm’ and its underlying objective knowledge situation now in the DSM medical meaning of ‘schizophrenia’.

DSM-IVTR (APA 2005) classifies ‘mental disorders’ by breaking down their characteristics into discrete medical entities. Patients’ ‘symptoms’ are then compared to this taxonomy in order to find the diagnosis that most closely matches. Within this taxonomy, ‘Schizophrenia’ is seen as the core diagnosis of the ‘Psychotic Disorders’ (pp297-343)¹², and accordingly, ‘Psychosis’ is seen as the key feature of the diagnosis. ‘Psychotic’ ‘positive symptoms’ – so-called because they are regarded as additional to ‘normal’ experience (APA 2005:299) – are thought to be ‘delusions or prominent hallucinations, with hallucinations occurring in the absence of insight into their pathological nature’ (p297). ‘Negative symptoms’, meanwhile, are thought to be ‘deficits’ to ‘normal’ behaviour, characterised by a lack of fluency of thought and speech and difficulty in carrying out goal-directed tasks (APA 2005:301).

In this brief overview we can see a ‘naïve realistic stance’ toward ‘psychotic’ experiences (Cromby & Harper 2009:338) in which ‘symptoms’ are viewed independently of existential content and context so that the underlying objective knowledge situation required by the ‘positivist technological paradigm’ that DSM is situated within can be attempted. However, to artificially ‘carve nature at the joints’

¹² Aside from Schizophrenia and its subtypes, this includes Schizoaffective Disorder, Schizophreniform Disorder, Delusional Disorder, Brief Psychotic Disorder, Shared Psychotic Disorder, Psychotic Disorder Due to a Medical Condition, Substance-Induced Psychotic Disorder, and Psychotic Disorder Not Otherwise Specified. This study only includes participants who have received the first two of these associated diagnoses. Schizoaffective Disorder, is considered a bridge (APA 2005:319) between the ‘schizophrenic psychoses’ and the ‘mood disorder psychoses’ (which are believed to be aetiologically distinct). For the sake of clarity, we should note that Schizophreniform Disorder is given as a diagnosis when ‘symptoms’ are observed to last less than six months (APA 2005:317-319). Henceforth, the core Schizophrenia diagnosis is focussed on here.

(Rapley *et al* 2011) in this way requires the excision of *Dasein* from both observed *and* observer, with the consequence that ‘seeing the world ontologically is... lost; and the subsequent interpretation of the world as made of substances is inevitable’ (Gelven 1989:66). This artificial excision lies at the core of three assumptions within psychiatry that Bracken *et al* (2012) believe to be erroneous.

(a) Mental health problems arise from faulty mechanisms or processes of some sort, involving abnormal physiological or psychological events occurring within the individual.

(b) These mechanisms or processes can be modelled in causal terms. They are not context-dependent.

(c) Technological interventions are instrumental and can be designed and studied independently of relationships and values (*ibid.*).

These assumptions encapsulate some of the key issues with medical meaning, and we will now examine them more closely by drawing on wider critical clinical discourses.

In regard to a), although never clearly stated, DSM-IVTR (APA 2005) makes frequent reference to biological origins of ‘schizophrenia’ (pp305-309), creating the impression that ‘it’ is an organic disease process which can be recognised by its ‘symptoms’. Yet, as Boyle (2002) and Joseph (2003) point out, biological research studies that start with the *a priori* assumption that ‘schizophrenia’ is a genetic disorder often wrongly attribute complex psychological inheritance to genes.

This critique appears to be supported by research that suggests that rather than genes dictating brain structure, and therefore ‘schizophrenic symptoms’, life experience

itself has a profound influence on the development of the brain. For example, neurological research shows a high incidence of trauma amongst those with the diagnosis (Picken *et al* 2010), and in particular, trauma caused by the deliberate actions of another (Newman *et al* 2010). Read & Bentall's (2012) review of research in this area shows a strong relationship between childhood trauma, such as such as neglect, poverty, bullying, and sexual abuse, and the development of 'psychosis' in adulthood. Janssen *et al* (2004) found this link to be dose respondent, where '[t]he odds ratio for 'mild abuse' was 2.0, but 48.4 for 'severe abuse' (p42). Conversely, the structure of the brains of those who are known to have experienced trauma have also been observed to be altered during psychotherapy (Damasio 1999, Fonagy *et al* 2002, Viamontes & Beitman 2009, Schore 2012). In summary then, there is strong evidence to suggest life experience might shape the *development* of 'substances', rather than being merely a passive expression of their predetermined nature, and so understanding the meaning of these experiences seems important. However, because biological psychiatry persists with assumption a) the attempt to understand 'schizophrenia' is locked into b), which tries to explain material brain mechanisms in generalisable causal terms, stripped of content and context. Accordingly, DSM focuses on '[e]nlargement of lateral ventricles... Decreased thalamic volume... Increased basal ganglia... Increased incidence of large cavum septum pellucidi' (APA 2005:305), rather than the life experiences that might have led to such structural developments.

Assumptions a) and b) then lead to assumption c): 'technological interventions', which is similarly problematic. For example, Joseph (2004) notes that flawed genetic research is used to validate pharmaceutical trials, which have been noted by Goldacre (2012), Kirsch (2009), Law (2006) and Whitaker (2010) to routinely manipulate

unfavourable data and conceal information about harmful side effects. As DSM-IVTR itself notes, these same side effects may appear similar to ‘symptoms’ of ‘schizophrenia’ (APA 2005:301). Long-term antipsychotic use has also been found to alter the structure of the brain, evidence that has then been erroneously used to support a genetic theory of ‘schizophrenia’ (Ross & Read 2004). When medical meaning dominates all stages of research, diagnosis and treatment then, we can see how a closed circle of knowledge is created, which then perpetuates the overwhelming bias toward research that looks for biological causes (Read *et al* 2001). In turn, this research continues to reinforce a), and so on. We will look more closely at the b) and c) segments of this circle in Chapter 7 in light of both the findings in Chapter 6 and the literature reviewed in Chapter 2.

Because NICE Guidelines for Schizophrenia (NCCMH 2010) are a powerful force in research and treatment, they exert an influence on the phenomenon researched here and so require a brief examination. The guidelines depart from the above medical meaning circle of knowledge by noting the effect of ‘social factors’ (p22) such as ‘environmental stressors’, ranging from ‘urban birth and rearing, social adversity and trauma, heavy cannabis use, migration and stressful life events (p23)¹³. However, ‘psychological factors’ overall are regarded as ‘problems in cognitive function’ and ‘are related to research in brain structure and function’ (p22), a notion which rests on assumptions a) and b). The circle is closed again by the NICE approach to treatment, in which medical-style ‘interventions’, such as medication are seen as ‘primary’ (p27). Psychological ‘interventions’, meanwhile, must adopt a similar ‘technological paradigm’ because they are required to:

¹³ Another area of divergence is the psychiatric definition of ‘schizophrenia’ used in the guidelines, which is the World Health Organisations’ (WHO) ICD10. However, NICE guidelines note that ICD10 and DSM-IVTR are largely concordant (NCCMH 2010:19).

[R]educe the impact of stressful events and situations; decrease distress and disability; minimise symptoms; improve quality of life; reduce risk; improve communication and coping skills; and/or enhance treatment adherence (NCCMH 2010:245).

Despite a ‘multidisciplinary’ approach involving psychiatrists, psychologists, and ‘national patient and carer organisations’ (p12), the NICE conception of ‘schizophrenia’ and its treatment seems to bear out Parker *et al*’s (1995) argument that psychiatry and psychology’s aims have become increasingly merged around, what is referred to here as medical meaning.

In summary then, medical meaning rests on the belief that an ‘objective knowledge situation’ (Gelven 1989:63) can be created in which both observer *and* observed are rendered *Dasein*-stripped ‘unmeaning’ ‘person-Things’ in order to ‘know’ something about what is observed. Models of causality and technological ‘interventions’ that are grounded on this ‘unmeaning’ then complete a closed circle of knowledge. This knowledge situation has led the ‘behavioural sciences’ to become dominated by, what anthropologist and social scientist Gregory Bateson (2000) describes as, ‘a mass of quasi-theoretical speculation unconnected with any core fundamental knowledge’ (p17). Moreover, far from being an ‘objective knowledge situation’, medical meaning is in fact a *subjective* meaning structure that comes loaded with cultural and political assumptions, priorities and agendas. We can now grasp more comprehensively the dynamics underlying the treatment impasse that Dillon (2009) described in Chapter 1.

What I was experiencing was never considered to be a natural and human response to things that had happened in my life (p190).

In this impasse we see how medical meaning is unquestioningly used to dominate another's personal meaning. Moreover, if this domination is not accepted, the experiencing person is deemed to 'lack insight' into their 'disease'. In the next section we will look more closely at how, for Heidegger, this kind of domination has crucial implications for care that is given to another and its impact on meaningful selfhood.

3.5. Heidegger's conception of understanding, possibility, meaning and care

It was noted above that it is through a conception of '*Dasein*-with', that we come to the interlocking concepts of understanding, possibility, meaning and care. In order to proceed, we first need to appreciate how authentic and inauthentic modes of *Dasein*, relate to these concepts.

For Heidegger, Being is always 'thrown into a world in which one has little say' (Gelven 1989:121). This 'actual world' (Heidegger 2008:240) is characterised by the 'impersonal prattle of the "they"' (Gelven 1989:73-74); for example, social conventions and rules, or in the case of the subject researched here, scientific *explanations* of 'schizophrenic' experience. For Heidegger, *eigentlich*, or authentic living, starts with the premise that to *eigen* ["own"] (Gelven 1989:70) a self involves two core principles. The first is that one must have an awareness of the *Befindlichkeit*, or 'state of mind' or 'actual', that one is caught up in (p80). The second is that one must be open to the 'existential' of *Verstehen* (p86), which is an understanding of the possibilities (both 'good' and 'bad') that extend ahead of oneself once one sees past this 'actual' and the associated 'They-self' that does '*not even... consider* such questions' (p119). In this sense the 'chief characteristic' of understanding is to '*project possibilities* (Gelven 1989:121) like a searchlight, illuminating what lies before *Dasein*'

(p89). This 'authentic mode' is 'the only genuine way in which one can be aware of the meaningful self' (p75). Foreclosing on this possibility drives the self into a defensive *uneigentlich*, or 'inauthentic', "non-self-mode" (Gelven 1989:73-74), in which the focus is not on 'my own Being', but 'the Being of "they"' (p121). In this inauthentic mode Being 'loses sight of the self' and covers it up (Gelven 1989:71).

Crucially, an awareness of the 'actual' that we are *always* to some degree caught up in may arise from its breakdown. To appropriate an analogy used by Gelven (1989:95-96), it might be only when a car breaks down that the driver lifts the bonnet and starts to think about *what* makes the car run, and *why* it has ceased to function. By moving away from the 'proximal' view (Heidegger 2008:155) that unblinkingly accepts 'actuality', and exposing oneself to its constituent parts, the possibility of *authentic* meaning arises. Thus, when we '*understand* the question of Being' we become 'aware of possibilities... other than the mode of the actual' (Gelven 1989:70) and the world then has the potential to be 'a kind of future world, yet to be realized' (p88). Becoming open to such possibility is 'the ground both of freedom and of truth' (p70).

For Heidegger, keeping possibility open is an essential act of care for both oneself and others. Conversely, closing possibility down and encouraging a flight into inauthentic living is a dereliction of care. Section 42 of *Being and Time*, '*the existential interpretation of Dasein as care*', helps us appreciate how deeply woven these concerns are. Heidegger (2008) cites a Latin myth in which 'Care' fashions a lump of clay into human form, which Jupiter then breathes life into. When Jupiter and Earth bicker over who should name this creation, Saturn arbitrates: Jupiter will receive the

creation's spirit on death, and Earth its body, '[b]ut since "Care" first shaped this creature, she shall possess it as long as it lives' (p243). Heidegger extrapolates that,

'[C]are' is seen here as that to which human Dasein belongs 'for its lifetime' It gets the name '*homo*' not in consideration of its Being but in relation to that which it consists (*humus*) (*ibid.*).

In essence then, man takes his form from the earth, but his Being is defined by care (*Sorge*)¹⁴, which for this reason is the 'the primordial existential of Dasein' (Gelven 1989:114). It is one's duty as a human being, therefore, to care both for oneself and for others by facilitating possibilities beyond the enslaving 'actual' state that we find ourselves in.

We can now grasp the implications of Heidegger's differing *modes* of care for another (*Fursorge*). On the one hand, *Einspringende Fursorge*, or 'intervening care' (Boss 1963:73), is a care that 'leaps in and dominates' and so may force another into 'inauthentic' living (Heidegger 2008:159). Returning to the example provided by Dillon (2009) above, care that dominates in this way might represent one way in which the personal meanings of those with the diagnosis are forcefully 'colonised' by the 'medical story' (McCarthy-Jones 2012:316), or what has been called medical meaning here. We should note, however, that this intervening impulse may also be

¹⁴ We should note that there are differing interpretations of *Sorge*. Burston (2000) interprets the *Being and Time* conception of *Sorge* as a 'vigilance' for oneself and others, but which might also be translated as "anxiety", or synonymous with 'will' (p116). However, he also notes that in Heidegger's later work the word has been interpreted by Arendt (1971) as 'the uniquely attuned and responsive person' who may be seen as a "shepherd" or "guardian" (Burston 2000:116). Gelven (1989) meanwhile, suggests that 'anxious' care might be assigned to the word *Bersorgen*, or 'concern about', while *Fursorge*, or 'solicitude', might be interpreted as caring *for* another. This accords with Macquarrie & Robinson (translators of Heidegger [2008]). In summary, for Burston, an earlier meaning of *Sorge* seems to be ascribed to intervening care, and a later meaning ascribed to anticipating care. For Gelven and Macquarrie & Robinson, the former seems bound up in *Bersorgen*, and the latter in *Fursorge*. However, since Heidegger uses *Fursorge* as the suffix for both modes of care, neither interpretation quite matches. Boss' (1963) interpretation retains this structure by using the *Fursorge* suffix to denote care for another, and the prefix, i.e. either *Einspringen* (intervening) or *Vorspringende* (anticipating), to determine the character or *mode* of the care. In the context of this study, it was this last interpretation that seemed the most useful.

found in approaches to care that do not so obviously dominate. For example, Heidegger (2008) singles out ‘empathy’ for particular scorn (p162), because it is easily ‘led astray and obstructed by the various possibilities of Being which Dasein itself possesses, so that a genuine “understanding” gets suppressed’ (p163). On the other hand, *Vorspringende Fursorge*, or ‘anticipating care’ (Boss 1963:73) ‘leaps forth and liberates’ because it ‘authentically’ gives back to another ‘for the first time’, so they may ‘become transparent’ to themselves in their care *for* themselves, and ‘become free for it’ (Heidegger 2008:159).

In the next section, we will explore these concepts through the prism of Laing’s work, which helps us to see how they translate into a psychotherapeutic approach to understanding experiences of ‘schizophrenia’.

3.6. Laing’s psychotherapeutic approach to understanding ‘schizophrenia’

While the existential phenomenology of Sartre, Buber, Tillich, Levinas and Jaspers are notable influences on Laing’s work, along with Kierkegaard, Nietzsche, Jung and others (Burston 2000), it is Heidegger’s bearing on Laing’s psychotherapeutic approach to understanding ‘schizophrenia’ on which we will focus here. This approach differs from an objective scientific position in three important ways. Firstly, observable behaviour is not seen as separable from experiences that underlie it, and so the focus on the former while ignoring the unobservable latter is seen as folly. Secondly, this underlying experience is not seen as generalisable, so in order to know something about it one must attempt to understand the existential situation in which it is located. Thirdly, the personal meaning arising from this situation is seen as very different from the meaning that the observer imposes on the behaviour observed. To look at these issues in more detail we

will briefly examine elements of *The Divided Self* (1965) and *The Politics of Experience* (1967), key texts in, what is referred to here as, Laing's 'early work'¹⁵.

In regard to the first two distinctions, it was noted earlier in this chapter that from a logical positivist position Ayer (1956) attempts to overcome the invisibility of inner experience by proposing it is knowable through the 'dimensions of our language' (p222) and other generalizable axioms. Rather than assuming inner experience can be generalisable in this way, Laing (1967) advocates a science of 'social phenomenology' which might look beyond the 'partial views and vistas' offered by seen behaviour (p17). For Laing, this science must *start* with experience – both the experience of the subject *and* the observer, because:

[B]ehaviour is a function of experience; and both experience and behaviour are always in relation to someone or something other than self (pp21-22).

This '*inter-experience*' is 'concerned with your behaviour and my behaviour as *I experience it*, and your and my behaviour as *you experience it*' (Laing 1967:17). In this sense, behaviour and experience are always in relation to *what* is experienced - one *Dasein* to another – rather than solely arising from one individual's 'substances'. For Laing, this model of 'inter-experience' is mirrored on an 'intra-psychic' level, since experience is not posited as inner, and behaviour as outer, rather, the two are inter-related as well (pp18-19). The implication of such 'inter-experience' can be seen in Laing's developing conception of 'schizophrenia' in the individual as a *manifestation* of

¹⁵ We should note these two texts are at either end of a period which saw the influx of other thinking (Bateson, Schilling, Hegel, Marx, etc), and resulted in a shifting position toward Heidegger that makes his debt ambiguous (Burston 2000:119). Laing's later work (and, it has to be said, elements of his early work too), which built on these evolving ideas, led to accusations that Laing might be closing down the meaning of 'schizophrenia' with the same kind of explanations he was critiquing.

a wider situation, as this extract from *Sanity, Madness and the Family* (Laing & Esterson 1964) illustrates.

The way in which a family deploys itself in space and time, what space, what time, and what things are private or shared, and by whom – these and many other questions are best answered by seeing what sort of world the family has itself fleshed out for itself (p 21).

There is not the space here for a digression into this concept of ‘schizophrenia’.

However, we should note that while this conception might start to close down the possibility of what ‘schizophrenia’ might be with theory,¹⁶ it has the benefit of looking beyond the medical explanation that ‘schizophrenia’ *arises* ‘from faulty mechanisms or processes’ (Bracken *et al* 2012:430). This allows for an interpersonal framework that might incorporate, for example, the impact of experiences such as trauma.

As for Heidegger, this framework provides a starting point for understanding another’s meaning. While the influence of Heidegger’s *Verstehen*, or understanding *qua* possibility, can be detected in Laing’s notion of authentic selfhood (along with Kierkegaard, Sartre and Winnicott), Laing does not make direct reference to it in terms of understanding another’s meaning. Instead, Laing references a similar concept: Dilthey’s (2010) *Verheistende*, or ‘empathic understanding’.¹⁷ Like Heidegger, Dilthey sought to understand another ‘humanly, as an expression of their

¹⁶ We do not need to concern ourselves with this theory here. However, we could summarise that this theory combined the elements mentioned in the previous footnote into a proposition that ‘schizophrenia’ in the individual, may in fact be a manifestation of interpersonal ‘double binds’ and ‘knots’. Laing proposed that these debilitating ontological states then become obscured from the ‘schizophrenic’ subject who experiences them by layers of ‘mystification’ – Marx’s term for a ‘plausible misrepresentation’ (Howarth-Williams 1977:46). For Laing, this mystification is both an act perpetrated by the person who wishes to obscure the double bind they have imposed on the ‘schizophrenic’ and a resultant state in which the ‘schizophrenic’ finds himself in.

¹⁷ While this position seems similar to Heidegger’s *Verstehen* understanding (Gelven 1989:80), as noted earlier in this chapter, Heidegger took issue with the term ‘empathy’ because, he argued, it has the capacity to lead astray and obstruct possibilities, with the consequence that ‘genuine “understanding” gets suppressed, and Dasein takes refuge in substitutes’ (Heidegger 2008:163). We should also note that Laing’s concern with understanding is not just derived from Dilthey, but also owes a debt to Buber’s (1970 [1923]) *I and Thou*, which contrasted the prevailing ‘I-It’ depersonalisation required by positivist science with a more human attempt to relate to the other on an ‘I-Thou’ level (Burston 2000:53). This concern becomes a preoccupation with the politics of understanding another person’s experience in Laing’s later work.

experience of the world... rather than as a sequence of mechanical or organismic processes governed by natural law' (Burston 2000:66). In this view, the exclusion of the hermeneutic "of the given, living whole" (Bultman *in* Laing 1965:32) effectively renders all secondary historical texts, (such as the patient's history, or theoretical interpretations), that are used to *explain* behaviour *meaningless*.

At the time of his early work, Laing was in a minority in believing such a framework could help one understand experiences of 'schizophrenia', even amongst those who were sympathetically aligned. For example, Dilthey's influence can be found in Jaspers' phenomenological approach to psychiatry, which sought to separate mental conditions that needed an *explanatory* framework, such as 'organic disorders', from conditions related to life experience, which required an *understanding* framework (Alanen 2009). Crucially, Jaspers believed that 'schizophrenia' belonged to the former, and so could not be understood. Although influenced himself by Jaspers, Laing disagreed with this position, and stressed that 'schizophrenia' was no less understandable than any other condition; an argument that is born out both by contemporary research into the relationship between trauma and 'psychosis' and the experiences researched here.

In regard to the third distinction we will examine an extract from Laing (1965), which has the dual function of illustrating all three distinctions together in a clinical setting. The extract centres on Laing's critique of a case presentation made to an audience of student psychiatrists by Emil Kraepelin, the father of modern 'biological psychiatry'. The presentation features a young man called Hans, who Kraepelin has diagnosed with '*catatonic excitement*', a diagnostic forebear of 'schizophrenia'. Kraepelin comments on

Hans' seemingly incomprehensible mumblings and his 'irrational' barking retort when asked his name, which, from Kraepelin's 'objective' position, seem the "sign[s]" of Hans' "disease" (p31). However, Laing argues that one is led to a radically different understanding if one sees Hans' behaviour as 'expressive of his existence' (*ibid.*).

What is the boy's experience of Kraepelin? He seems to be tormented and desperate. What is he "about" in speaking and acting in this way? He is objecting to being measured and tested. He wants to be heard (*ibid.*).

In imposing pre-existing 'categories of thought' on Hans (p33), both the historical experience that might have led to his initial diagnosis, and the experience of his humiliating presentation to the gallery, have been objectively excised from the knowledge situation because they are deemed to be irrelevant texts. In the context of this study, we could say Laing presents Kraepelin's analysis as a failure to appreciate Hans' personal meaning as *primary*. Instead, Hans' behaviour is *explained* with pre-existing categories of thought ('secondary texts' such as theory) that we might call here the subjective lens of medical meaning, through which Kraepelin sees 'signs of schizophrenia'. This meaning therefore closes down understanding *qua* possibilities *beyond* itself. In this configuration 'data' supporting these pre-existing 'categories of thought' are 'all ways of *not* understanding him' (*ibid.*). The implications of failing to understand do not end here. As Burston (2000) notes, from Laing's perspective, Hans' disturbed condition may in fact be a manifestation of '*our* inability or unwillingness to understand *him*' (p69). Transposed into Heidegger's models of care, one might say that Hans' disturbance might be an expression of having his personal meaning dominated by a care that intervenes.

Although Laing (1965, 1967) does not refer explicitly to Heidegger's modes of care, Burston (2000) notes that Laing chose to characterise his therapeutic approach within the Heideggerian idiom of "solicitude" (p36), or *Fursorge*. Crucially, Laing seemed critical of an intervening approach to care, because to *not* see another as a range of possibilities beyond an enslaving 'actual' (or 'pre-existing categories of thought') seems an uncaring violation. When transferred into a therapeutic encounter, the implication is clear.

Any technique concerned with... an object-to-be-changed rather than a person to be accepted simply perpetuates the disease it purports to cure (Laing 1967:45).

While Heidegger's conception of anticipating care is not mentioned either, it is clear that Laing regards helping another to become authentically his *own*, and 'free for it', a guiding principle of his therapeutic approach. In regard to both modes then, Laing's position on care seems essentially Heideggerian (Burston 2000:54).

3.7. Conclusion

In this chapter Heidegger's existential-phenomenology, in conjunction with critical clinical discourses, has been used to both deconstruct the medical meaning that is used to explain experiences of 'schizophrenia' and to create a knowledge framework in which the personal meaning of experiencing persons might be understood.

Crucially, to *explain* another's behaviour with medical meaning and to attempt to *understand* another's personal meaning have been argued 'to see and to hear in radically different ways' (Laing 1965:33), both of which may then impact on the 'behaviour' that is 'seen and heard'. When these opposing approaches are deployed in care for another,

there may be important consequences. To objectively *explain* another's experiences with medical meaning 'uncaringly' (in a Heideggerian sense) distances the observer from that person's personal, or 'proper meaning' (Gelven 1989:95), and renders them an 'unmeaning' 'person-Thing'. In forcing this kind of explanation on another 'intervening care' may be experienced as a 'colonisation' of meaning in which authentic selfhood is usurped by an inauthentic 'non-self', reinforce an enslaving 'actual', and foreclose on possibility and freedom. When medical meaning and intervening care are deployed in the treatment of 'schizophrenia' they may perpetuate 'the disease it purports to cure' (Laing 1967:45). In contrast, a care that anticipates may fulfil the 'primordial existential' of care, because it encourages an *understanding* in which possibility is kept open. Helping another to look beyond an enslaving 'actual' in this way, and encouraging them to develop a personal meaning that is grounded in possibility and is authentically their *own*, may then help free 'the Other in his freedom for himself' (Heidegger 2008:159).

In Chapter 7, these issues are discussed in more depth in light of both the literature detailed in Chapter 2 and the findings presented in Chapter 6. In the next chapter, the search for a methodology that might bear the concerns raised in this chapter in mind is described. Polanyi's 'third way' between modernism and postmodernism (Gill 2000), which underpins heuristic methodology (Moustakas 1990), is explored as one way of developing an understanding approach to the phenomenon researched here.

Chapter 4

Understanding personal meaning – finding a suitable methodology

4.1. Introduction

In preceding chapters, we saw how this study came about, and then explored the literature that represented the phenomenon researched here, and some of the reasons why this literature might lack the kind of detail required. This then led to the attempt to create a knowledge framework for understanding the psychotherapeutic experiences of those with the diagnosis. In this chapter, the process that led to choosing a methodology with which to empirically research this phenomenon is described (4.2.). Several research methodologies were considered, and this process led to heuristic methodology (Moustakas 1990) being selected. Because of the personal, reflective approach to knowledge in heuristic research, this process is described in some detail (4.3.). The second half of the chapter (4.4.) then explores the ‘concepts and processes’ involved in heuristic methodology (pp15-26), together with their underpinnings, most notably Polanyi (1969, 2009) and Rogers (2004). The heuristic method that was used to carry out the research is detailed in the next chapter.

4.2. Study genesis

This study has its roots in a previous piece of heuristic research, which asked ‘*What relationship, if any, is there between the way we treat people and “The Treatment” in Psychotherapy?*’ (Cotton 2008). This question was influenced by Laing’s (1965, 1967) thinking on the ethics of psychotherapy treatment, and was explored by researching the experiences of ex-residents of Kingsley Hall, the Philadelphia Association’s (PA)¹⁸ 1965-70 experimental therapeutic community (TC). Several of Laing’s colleagues were also interviewed, along with a resident in a contemporary TC. Interviews were videotaped, and formed the basis of a parallel Wellcome Trust funded multimedia project. This involved writing a screenplay, *Do Not Adjust Your*

¹⁸ Laing was a founding member of the PA and the figure most closely identified with Kingsley Hall.

Mind, which dramatised the events of Kingsley Hall (and whose on-going redrafting has occurred alongside this study); making a documentary film about Laing's work; and developing material for a book based on the research¹⁹. This parallel approach to creative and scientific research continued throughout the course of this study. To explore how this approach contributed to my autobiographical connection to what is researched here, a case for using the first person needs to be made.

Case for using the first person

It has been noted that an objective approach to research necessitates rendering both researcher and researched 'person-Things' (Heidegger 2008:155). Writing in the more dispassionate third person would seem in keeping with this rendering. Using the first person, however, seemed more in keeping with my attempt to reflect on being on a more equal footing with participants as a *Dasein*-with (*ibid.*). However, it is also acknowledged that this attempt may be no more than lip service, while using the dressing of the first person to appear more 'alongside' participants, while presenting my own 'story' through their words. These issues are discussed further in Chapter 7.

While Moustakas himself (1961, 1968, 1981, 1990, 1994) makes no mention of which person should be used in heuristic research, where Moustakas (1990) cites his own research, for example (p30), the first person is used, suggesting that its use is sanctioned. Moreover, the de-personalising third person seems at odds with the heuristic emphasis on self-processes and 'personal journey of discovery' (McLeod 2001:135), as well as the arguments raised in previous chapters.

¹⁹ This was published as *Laing and the Treatment is the Way we Treat People* (Cotton & Loewenthal 2011).

Autobiographical connection to research

Wary of the associated stigma, my experience of ‘being a psychiatric patient’ in my early twenties was disclosed in Cotton (2008) with some reluctance. Yet this reluctance is at odds with the way that I view the experience as the making of me as a young adult, and then later as a psychotherapist. In the six years since Cotton (2008), rather than this self-disclosure feeling like an uncomfortable requirement, my autobiographical connection to the phenomenon researched here seems more closely aligned with my own on-going ‘research process’. This process, which was briefly described in Chapter 1, played an important part in developing the research question explored in this study.

One participant in Cotton (2008) spoke about how his Borderline Personality Disorder (BPD) diagnosis seemed to fill the identity vacuum that had been left by what he was experiencing, with unforeseen consequences.

Once you’ve got the diagnosis, you are everything to do with that diagnosis. I’ve certainly had a lot of things written about me that just aren’t true, and they’ve only made sense once I’ve read the diagnostic manual [DSM-IV]... (Gary Cairney *in* Cotton & Loewenthal 2011:98).

Perhaps influenced by my own experiences, this extract seemed to crystallise my growing interest in what was described in Chapter 1 as the gap between professional and patient discourses. This impacted on my research process in two ways. Firstly, I began to explore this theme in relation to ‘schizophrenia’ in the screenplay aspect of the Wellcome Trust project. Not satisfied that I had enough ‘lived experience’ of the professional’s side of the story, I found work project managing a residential TC for clients with the diagnosis. Trying to bring stability to a chaotic, traumatised group of

adults (staff as well as clients, at times, it should be noted), some heavily medicated, others with substance addictions, forensic records, and histories of violence and abuse, was a steep learning curve. Combined with working closely with Community Mental Health Teams (CMHTs), sectioning tribunals, police, criminal courts and hospitals, this experience threw me deep into the *Realpolitik* of the mental health system.

One consequence of this experience was that the focus of documentary aspect of the Wellcome Trust project began to change. While an important legacy of Laing's work was helping to make the psychoses '*intelligible*' (Bentall 2005: 227), it became clear that the first person perspective of those with the diagnosis was the most potent *and* appropriate way of communicating this intelligibility to a mainstream audience. The final film, *There is a Fault in Reality* (Cotton 2010), told this story in detail from the perspective of three people with the diagnosis. Two main themes emerged from this story.

1) Voices and other 'schizophrenic' phenomena have a meaning that is often related to earlier trauma.

2) In addressing and working through this meaning recovery from 'schizophrenia' is possible.

During research and filming for the documentary it became clear that psychotherapy had been an important aid in this meaning-making process for some, yet there seemed little scientific literature that depicted this process in detail from the perspective of those with the diagnosis. Important questions seemed under-explored. What do those

with the diagnosis understand to be happening in the psychotherapy process? What do they consider both helpful and unhelpful? How might addressing meaning be helpful?

In essence, then, the experiences of being a psychiatric patient, a psychotherapist, project manager and filmmaker working with those with the diagnosis brought four perspectives of enquiry together, which contributed to the developing question. Rather than further developing the research question explored in Cotton (2008), as originally intended, a new research question emerged: ‘What are the psychotherapeutic experiences of those with a “schizophrenia” diagnosis?’ The next step was to find a suitable methodology with which to research this question empirically.

4.3. Search for a suitable methodology

Consistent with the arguments raised in earlier chapters, McLeod notes that positivist science is ‘seen as philosophically and politically inappropriate when applied to the study of human action’ (McLeod 2003:7). By contrast, a qualitative approach might be characterised by researchers attempting to ‘understand individuals’ perceptions of the world’ (Bell 2005:7). McLeod (2001) suggests that this kind of knowledge might be generated in three main areas. Firstly, ‘*[t]he ontological question*’, which involves asking what can be known about “how things really are” and “how things really work”. Secondly, ‘*[t]he epistemological question*’, which asks ‘What is the relationship between the knower and would-be knower and what can be known?’ And Thirdly, ‘*[t]he methodological question*’: ‘how can the... would-be knower go about finding out whatever he or she believes can be known?’ (p55). This qualitative approach seemed the most suitable framework for carrying out the aims of this study. Chapters 2 and 3 looked in detail at these first two questions. Because the search for a suitable methodology (i.e.

the third question) raised important issues about these first two questions, the process of this search is discussed now in some detail.

Discourse Analysis

Discourse Analysis (DA) was the first methodology to be considered, and seemed suitable for several reasons. Firstly, in being ‘driven as much by an intuitive feel for what might work, rather than any pre-determined analytic rules’ (McLeod 2003:101), DA seemed compatible with the kind of flexible approach to exploring life stories which had been fruitful in Cotton (2010). Secondly, in examining ‘naturally occurring talk’, rather than attempting to reveal structures within ‘the client’s head’ (McLeod 2003:102), DA seemed compatible with the arguments made in Chapter 3. Thirdly, in walking a difficult line between postmodernism and its roots in positivist psychology (p103), DA offered an opportunity to examine how the tension between the two played out in a phenomenologically-orientated piece of research. While the first two reasons seemed to further the empirical aim of this study, the last point seemed to further the epistemological aim.

However, the process of making Cotton (2010) raised issues with this approach. During interviews in that film, engaging in immersive, mutually disclosing dialogue seemed to help the participants talk about their stories more openly. Trying then to balance a fair representation of the participants’ meaning with the need to engage an audience in a ‘dramatic’ story threw up challenging questions about editorial power, and the psychotherapeutic ethics by which I felt bound as a filmmaker (Cotton & Sandberg 2011). I was reminded of Levinas’ entreaty that in ‘regarding the face of the Other’ (Loewenthal & Snell 2003:150) there is a moral imperative to put them first.

Imagining the text of the film's participants analysed in a style similar to Gee's (1999) DA of a 'schizophrenic' participant's interview text, for example, left me with a deep sense of unease. This self-dialogue (Moustakas 1990:16-20) raised four core issues with continuing to use DA as a method.

1) In an attempt to avoid reductive, totalising theories made by positivistic psychology about structures 'within the client's head', does DA merely shift this same objective way of looking onto cultural constructions revealed by language?

2) Does this then reinforce the idea that the DA researcher is positioned as the dispassionate, 'person-Thing', 'researcher-who-knows'?

3) Is it ethical to gain the trust of an interviewee, engage in a form of horizontal enquiry, only to take a 'superior' analytical stance when subjecting their 'text' to analysis?

4) '[T]here are severe problems involved in making sense of reflexivity from a rigorous discourse-analytic perspective' (McLeod 2003:100). Would DA's 'ironic semi-reflexive teasing' (p104) sit too uncomfortably with my attempt to place myself authentically within the research? Would there then be space to reflexively explore this?

These issues led me to abandon DA as a method and to review phenomenological methodology again.

Phenomenological methodology

Heppner *et al* (1992) argue that phenomenological research methods attempt to ‘understand how participants make meaning of and through their interactions’ (p196). Finlay (2009) proposes that this understanding process takes the form of ‘a return to [the] embodied, experiential meanings’ (p1) of participants. For Spinelli (2005), this return involves ‘illuminating and disclosing the meaning structures of lived experience’ (p131). For McLeod (2001), this phenomenological focus on understanding and disclosing the meaning of experience has yielded useful knowledge about ‘constructs such as anxiety, depression and schizophrenia’ (p59). In essence then, this conception of phenomenological methodology seemed to satisfy the issues raised in Chapter 3. However, by *what* process this ‘clarifying’ of meanings might take place, and *how* this illuminating and disclosing might be structured by the researcher becomes crucial.

Finlay (2009) raises six core questions about how phenomenology should address these concerns. Of these, the last five are relevant here. Firstly, should the aim be to produce a ‘general (normative) description of the phenomenon’ or is arriving at particular, or ‘idiographic’ description ‘legitimate’? Secondly, to what extent should interpretation enter description? Thirdly, should researcher subjectivity be set aside, or foregrounded? Fourthly, should it be more “science” than “art”? And finally, is it a modernist, or postmodern project, or is it neither (p1)? As noted in Chapter 3, Husserl’s phenomenology takes a very different approach to Heidegger’s, and so the answers to these questions depend on which perspective within the phenomenology spectrum one is asking them from. The methodologies reviewed below occupy varying positions in this spectrum, and so address these questions in different ways.

Moustakas (1994) breaks phenomenological research methods into five main approaches: Ethnography, Grounded Research Theory, Duquesne University's Phenomenology (also known as Empirical Phenomenology [EP]), Hermeneutics and heuristics. The last three were considered for this study, along with Smith *et al*'s (2009) Interpretive Phenomenological Analysis (IPA).

(EP) (Georgi *et al* 1979) relies on Husserlian description and reflective analysis. However, placing Husserl's transcendental phenomenology at the heart of the method leaves little room for the possibility that 'people are interpreting beings' (McLeod 2001:61), not least the researcher. There seemed little provision in the method to explore this issue reflexively; moreover, Husserl's proximity to Cartesian dualism was problematic considering the arguments raised in Chapter 3.

Hermeneutic methodology seemed compatible with the 'phenomenological-hermeneutic' of Heidegger's Dasein (Craig 2007:12). Additionally, the 'Interrelationship of science, art, and history... at the heart of the hermeneutic design and methodology' (Trumbull 2005:114) seemed to offer a framework for including knowledge gained from the parallel Wellcome Trust project. This led to three phenomenological hermeneutic approaches being considered.

Laing, Philipson and Lee's (1969) Interpersonal Perception (IP) methodology emphasises researching the interpersonal, and, when considering this in conjunction with Laing's influence on the genesis of this study, reviving this method seemed appealing. However, a large number of participants are required and a complex modernist quantitative methodology is used, neither of which served the aims of this

study. Smith *et al*'s (2009) IPA draws on both Husserl and Heidegger within a hermeneutic framework of interpretation, and was considered next. While IPA seemed to move beyond the issues with Giorgi *et al*'s (1979) EP, it seemed incompatible with the need for free-ranging interviews, and lacked provision for reflexivity about preconceptions the researcher to transparently include their own preconceptions (Thomas & Lowenthal 2007:132). Finally, Greenwood & Loewenthal's (2005) case study method was considered, which aims to build a foundation of knowledge 'drawn from experience' (p37). The emphasis on idiographic meanings was attractive, along with the methodology's referencing of Dilthey's (2010) empathic understanding. However, the methodology seemed best suited to a single case study, and required another method for collecting data. These aspects combined made it unsuitable.

Moustakas' (1990) heuristic methodology was the last to be considered. Using this method in Cotton (2008) had been a fruitful, but frustrating experience, and I was unwilling to consider it again. However, the process of making Cotton (2010), and the issues raised by DA methodology led me to reconsider. Re-reading the literature underpinning heuristic research, the parallels between Steinbeck & Ricketts' (1941) immersive ethnographic research and the approach to making Cotton (2010) were striking. Polanyi's underpinning philosophy also struck a deeper chord on this re-reading, along with Rogers' (2004 [1961]) appeal for a more humanised form of behavioural science research, undertaken by a 'disciplined, open-minded individual' (Rogers *in* Moustakas 1968:116). A detailed description of the methodology follows now, concluding with a summary of how it satisfies the five questions raised by Finlay (2009) earlier.

4.4. Heuristic Methodology

How the methodology came about tells us something of its ethos. Initially, the methodology grew out of Moustakas' desire to use his own experiences as admissible research data (Moustakas 1968:xi). This aim is characterised in his nascent heuristic study, *Loneliness* (1961), as 'an inquiry or search, perhaps a personal disclosure into the meaning and essence of loneliness itself' (pxii-xiii). In *Individuality and Encounter* (1968), Polanyi's work provides an epistemological grounding for this aim, and Rogers both deepens the humanist ethic and provides a phenomenological method. 'Heuristic Research' (Moustakas 1981), a chapter in *Human Enquiry: a sourcebook of new paradigm research* (Reason & Rowan eds.) refines this approach. The final formulation appeared as *Heuristic Research* (1990), the methodology used here. In this progression, we can see both the attempt to explore the meaning of a phenomenon through a personal approach to knowledge, and the attempt to create a more human form of scientific enquiry. Examining in more detail the 'concepts and processes' (Moustakas 1990:15) that inform the methodology helps us to understand how this attempt is made. Because the decision to select this methodology was partially informed by the issues raised in the last chapter, where relevant they are referenced.

Identifying with the Focus of Inquiry²⁰

This process encourages an immersive 'exploratory open-ended inquiry' that enables the researcher to 'get inside' the research question. The medical researcher Jonas Salk's (1983) work, *Anatomy of Reality*, is cited as an example. Here, Salk describes "the inverted perspective" of creatively imagining himself as "a cancer cell, for

²⁰ The American spelling is used only when quoting Moustakas (1990) directly, otherwise the UK form, 'enquiry', is used. A similar arrangement is used for the heuristic concept of 'Focusing', which takes the UK form, 'focussing', elsewhere in the text.

example”’, in order to gain a deeper insight into how the cell might work (Salk *in* Moustakas 1990:16).

Self-Dialogue

Rogers’ emphasis on entering into a process of discovery that is ‘rooted in the self’ (p17) provides the starting point for a ‘dialogue with the phenomenon’ which speaks directly to one’s own experience’ (p16). From this dialogue, understanding is extended ‘through the eyes and voices of others’ (p17). This ‘heuristic process’ is argued by Craig (1978) to be common to all scientific enquiry in the way it moves back and forth between a part of the experience and the whole. We can see the significance of this action in the way that heuristic methodology uses tacit knowledge.

Tacit Knowing

Polanyi’s (1969, 2009) concept of tacit knowledge is also considered a heuristic process that ‘guides the researcher into untapped directions and sources of meaning’ (Moustakas 1990:22). To understand both the concept and process, we need to look at Polanyi’s model of knowledge in more detail.

Whereas science tends to focus on *explicit* knowledge, Polanyi (2009) argues that *tacit* knowledge is a realm in which ‘*we can know more than we can tell*’ (p4). In this realm Polanyi (1969) makes a distinction between the *proximal* term, which consists of ‘things seen in isolation’, and the *distal* term, which consists of ‘the same things seen as a coherent entity’ (p140). This ‘dimensional model of reality’ is not static, rather a constantly moving integration of the three dimensions of *awareness*, *activity*, and *cognitivity* (Gill 2000:31).

In the *awareness* dimension, proximal and distal terms characterise the opposing poles of *subsidiary* and *focal* awareness respectively. These types of awareness are placed in a ‘vectorial and mediational’ arrangement (Gill 2000:35) in which ‘Lower principles’, for example, the letters that form the words on this page, are integrated by social interaction, followed by the ‘higher principles’ of letters forming words, then words forming a language. In this sense, we attend *to* the focal knowledge of language *from* the subsidiary awareness of letters, words, grammar, speech, etc. Significantly, this operation is only made possible by the integration of the remaining two dimensions, which mirror this structure. For example, the awareness dimension intersects with the *activity* dimension to produce speech, and *cognitivity* dimension to produce both tacit and explicit forms of knowledge.

This dimensional model negates the need for a Cartesian mind-body split because these realms are integrated and can never act independently of the body. Gill (2000) offers a useful metaphor for this integration. In Bergman’s film, *Wild Strawberries* (1957), the *geographical* journey undertaken by the professor to collect his award becomes the *action* through which the *existential* journey of the professor reflecting on his life is possible. In this sense, both journeys are not independent of each other; one is mediated by the other and vice versa (p35), and if we attempt to turn our gaze solely toward the subsidiary aspects alone (i.e. the geographical journey) the story becomes meaningless. Extending this metaphor, we might say that an objective approach might be to focus on the subsidiary action of the journey/behaviour, because this more ‘tangible’, and therefore measurable, aspect of the phenomenon suggests ‘a true conception of things’ (Polanyi 2009:19). However, Polanyi (1969) makes clear

that such thinking is ‘mistaken’, because it misses the meaning ‘these events have for the person’ (p148).

This critique is to some degree confluent with the argument raised in the last chapter. Continuing with Gill’s analogy, Heidegger might say that when the present-at-hand view of the professor’s physical journey is divorced from a ready-at-hand view of the world as he uses it (the existential journey), the former alone tells us nothing of the journey’s ‘proper meaning’ (Gelven 1989:95). Laing, meanwhile, might say that the objective scientific focus on the professor’s ‘behaviour’ ignores its complex interplay with his underlying experience (for example, the life events that led to him collecting his award). The process of ‘indwelling’, described below, both reveals further parallels between Polanyi, Heidegger and Laing, and illustrates how tacit knowledge is used.

Intuition

This process forms a bridge between tacit knowledge and ‘observable, describable... explicit knowledge’ (Moustakas 1990:23), which enables constant movement between these dimensions. In this context intuition ‘guides the researcher in discovery of patterns and meanings that will lead to enhanced meanings, and deepened, extended knowledge’ (*ibid.*).

Indwelling

This involves the researcher ‘turning inside’ himself, in order to ‘dwell inside the subsidiary and focal’ aspects of the experience (Moustakas 1990:24). To understand

this ‘painstaking, deliberate’ process (p25), we need to briefly turn to Polanyi’s concept of indwelling.

For Polanyi (2009), a stick *as an object* has quite a different meaning once we *use it as a tool*. This is because when we use it as a tool, we use it in the way we use our own body (p16). Therefore, when we use a stick/tool/theory at the proximal term of tacit knowing, ‘we incorporate it into our body – or extend our body to include it – so that we come to dwell in it’ (*ibid.*). In this sense, indwelling is the process by which ‘we come to’ live in ‘the things and ideas, people and institutions’ that characterise our world Gill (2000:39). As we integrate layers of this kind of knowledge, they sink from consciousness, yet our perception is still filtered through this knowledge. By definition then our perception is ‘active’, but in a way that is not always explicitly known to us. This is very different from an objective model where the observer and observed are considered passive, neutral receivers of the ‘out there’ world. To place this in an illustrative context, it will be helpful to return to Gill’s *Wild Strawberries* analogy. As noted above, an objective view misses the focal, or gestalt, meaning of the professor’s journey, because it focuses on the measurable physical, ‘behavioural’ journey, rather than the existential one. Now, because the objective observer fails to grasp the professor’s ‘indwelling’ experiences, he is instead seen as ‘an object or as a machine’ (Polanyi 1969:148), which further alienates the observer from the meaning of the professors’ actions, as they might mean to him. Finally, because the objective observer is employing their own ‘interiorized’, ‘indwelling’ model of knowledge (Polanyi 2009:17) their supposedly objective gaze is really an active, subjective filter that shapes how the professor’s behaviour is *interpreted*. However, because this filter is interiorised it is tacit, so the objective observer is unable to reflect on their

embodied subjectivity. Moreover, even if such knowledge became explicit, the objective observer may be unable to reflect on *not thinking* about their interiorised knowledge, because such reflexivity is beyond their indwelled objective framework.

This model of indwelling suggests further convergence with Heidegger and Laing. For Heidegger, Polanyi's indwelling might be loosely equated with the notion that 'knowledge is always, to some extent, influenced and characterized by the knower' (Gelven 1989:63), while for Laing (1965) it might be equated with 'pre-existing categories of thought' (p33). Laing suggests that such tacit indwelling may also have an important impact on the person observed, because 'both experience and behaviour are always in relation to someone or something other than self' (pp21-22), or as Heidegger might say, in *Dasein* Being-with, 'Others are encountered *environmentally*' (p155). However, because we cannot look at ourselves 'proximally' (i.e. directly, and in isolation), we can only truly "come across" ourselves when *Dasein* 'looks away' from '[e]xperiences' and the 'centre of its actions' (*ibid.*). Transposed back into Polanyi's model, this might read something like, 'When we look away from what we think we explicitly know about ourselves and the experienced researched, the tacit dimension might reveal itself, and in so doing we might know something more comprehensively about both'. As a heuristic *process*, we can see now how by dwelling in their *own experience* of the participants' experiences, the researcher moves back and forth between the subsidiary and focal aspects of these experiences, and draws on 'every possible nuance, texture, fact and meaning' (Moustakas 1990:24). In so doing, a 'deeper, more extended comprehension' (*ibid.*) of the phenomenon might be facilitated.

Focusing

This process is designed to enable the researcher ‘to determine core themes’ about an experience, refine their meanings, and ‘achieve cognitive knowledge’, by removing extraneous ‘clutter’ (Moustakas 1990:25). The process is grounded in the work of philosopher and psychotherapist, Eugene Gendlin (1962), who proposed that personal experience is prior to all of the external structures that might help us to conceptualise *what* we experience. In a later work, *Focusing* (1978), Gendlin arrived at a similar position to Polanyi in proposing the titular method as a way of accessing the ‘felt sense’ of this prior experiencing. Moustakas (1990:25) develops this concept into a five-step process, which is summarised here, as follows.

- i) ‘Clearing an internal space’
- ii) ‘Getting a handle on the question’
- iii) ‘Elucidating its constituents’
- iv) ‘Making contact with core themes’
- v) ‘Explicating the themes’ (*ibid.*).

Internal Frame of Reference

Drawing on Rogers, this concept and process emphasises the importance of empathically understanding the experiencing person’s ‘phenomenal world’ and their ‘internal frame of reference’ (Moustakas 1990:26). Like Polanyi, Heidegger and Laing, Rogers recognises the limitations of objective approaches for knowing about human experience, and adds an important ethical dimension for Moustakas, both in terms of how participants are treated, and how “‘the scientist as a human being’”-researcher (Rogers *in* Moustakas 1968:116) positions himself in relation to them.

Although not mentioned in the above heuristic concepts and processes, two further influences on heuristic methodology are relevant here.

Other heuristic influences

Steinbeck & Ricketts' (1941) ethnographic study, *The Sea of Cortez*, is cited as an example of a dedicated personal search. Here, researchers are encouraged to enter into an intimate relationship with the thing to be known, to allow themselves to be changed by the process, and to “not be betrayed by this myth of permanent objective reality” (Steinbeck & Ricketts *in* Moustakas 1968:110). This sentiment echoes Rogers' ‘dedicated, personal search’ (Rogers *in* Moustakas 1990:98), and Polanyi's assertion that in discovery through tacit knowledge “I shall never see the world again as before... I have crossed a gap, the heuristic gap, which lies between problem and discovery” (Polanyi *in* Moustakas 1990:56).

Finally, in keeping with the Humanist psychology discourse in which heuristic methodology is positioned, Maslow's (1956) ‘research on self-actualising persons’ is cited (Moustakas 1990:9) as an influence in his introduction to the method. Other less prominent influences are also cited; however, these are too numerous to mention. Maslow is singled out here because his emphasis on the primacy of experiencing, before “words, labels, concepts, symbols, theories, formulas, sciences” and other “paraphernalia” (Maslow *in* Moustakas 1990:17) occupies a similar position to Gendlin, Polanyi, Rogers, Heidegger and Laing.

Summary of heuristic methodology

Taken together, these concepts and processes form the basis of a methodology that seemed to further the aims of this study. Rather than attempting to carry out phenomenological research in a way that might sit within a modernist framework, in the manner of IPA, EP and Laing's IP, for example, heuristic methodology presents 'a way of engaging in scientific search' through creative processes, 'self-enquiry and dialogue with others' (Moustakas 1990:15). This methodology seemed to accommodate the desire for a creative-scientific approach to research, in which meaning might be explored through free-ranging discussion. In recognising that the 'passionate contribution of the person knowing to what is known' is not merely a piece of subjective 'contamination' (Moustakas 1981:211), and that knowledge gained in this process also brings the researcher to 'realizations relevant to their own experiences and lives' (Moustakas 1990:9), heuristic methodology also seemed to accommodate my own on-going research process.

Viewed together these components of heuristic research might answer the five questions raised by Finlay (2009) earlier in the chapter, in the following way. Heuristic methodology aims to foreground researcher subjectivity reflexively; emphasises relationship over objectivity; and takes a postmodern, descriptive approach to 'idiographic' *meanings*, rather than a modernist explanatory approach to 'normative' *meaning*. Summarised in this form, one could argue that heuristic methodology might enable the researcher to be less caught up in the need to use experience as 'evidence' (Laing 1967:16). Although this does not conclusively address the issue raised by Laing, it should be noted that Laing often seemed to contradict himself on this very point.

4.5. Conclusion

In this chapter, we have seen how the ontological and epistemological questions raised in this study stemmed from a personal research process, which in turn helped to shape the research question explored here. The search for a suitable methodology to ask this question in a way which would facilitate an understanding of the participants' personal meaning led to rejecting DA, and to re-examining phenomenological research methods. What was learned in this process led to a greater understanding of the ontological and epistemological questions raised, and in turn, led to selecting heuristic methodology. This methodology seemed both compatible with the epistemological and ontological arguments raised in previous chapters, and to offer a suitable framework for carrying out the empirical aims of this study.

In terms of the epistemological grounding of heuristic methodology itself, while several phenomenological discourses are referenced by Moustakas (Rogers, Maslow, Gendlin), it is not clear exactly where the methodology sits within the phenomenology spectrum. Moustakas (1990) makes no direct mention of Heidegger, however, Moustakas (1994) makes a lengthy distinction between heuristic methodology and EP, which relies on Husserl's transcendental method, and which as noted in Chapter 3, was revealed to be problematic in light of Heidegger's *Dasein*. In summary then, a deeper investigation of heuristic methodology has revealed a degree of convergence between Polanyi, its principal epistemological underpinning, and Heidegger and Laing.

The heuristic concepts and processes explored in this chapter inform the six 'phases' (Moustakas 1990:26-32) of heuristic research which were used to carry out the

research. These phases are detailed in the next chapter, along with ethical issues, participant sampling and data collection.

Chapter 5

Research Method

5.1. Introduction

In the last chapter we saw how seven concepts and processes (Moustakas 1990:15-27) are central to heuristic methodology. This chapter details how the method was used to carry this research out. Section **5.2.** begins with a description of how the ‘six phases’ that comprise heuristic ‘research design’ (p27) were used here, from developing the research question to analysing the resultant data. Section **5.3.** then describes how participants were selected, inclusion and exclusion criteria, and sampling methods used and **5.4.** details methods of data collection. Ethical issues are discussed during each relevant section. So that the reader can follow more clearly how the eight ‘procedures for data analysis’ (pp51-52), which drew on these phases, led to the findings, these are presented together in the next chapter.

5.2. Six phases of heuristic research

These phases ‘guide unfolding investigations’ (Moustakas 1990:27) throughout heuristic research, and draw on the seven ‘concepts and processes’ of heuristic research (pp15-27) detailed in the last chapter. The examples that Moustakas gives for the first three phases (pp27-29) relate to the development of the research question, and the final three (pp29-32) relate to data analysis. The description of how these phases were used in this study follows this pattern.

Initial engagement

Heuristic inquiry begins with an ‘initial engagement’ with a question that has been a ‘personal challenge and puzzlement in the search to understand one’s self and the world in which one lives’ (Moustakas 1990:15). In Chapters 1 and 4 we saw how the

four aspects of my autobiographical connection to the research all fed into this search, and shaped the development of this study.

The research question itself appears simple, but in actuality, it took months of intensive self-dialogue to formulate a question that was both open enough to allow free-ranging conversation with participants, and containing enough to ensure interviews remained focussed on the phenomenon researched. Although DA methodology was rejected in the early stages of this study, the questions raised by it were also an important part of this initial engagement phase.

Immersion

Once the research question was found, a period of immersion followed, in which ‘virtually anything connected with the question becomes raw material’, with the aim of developing the researcher’s ‘alertness to all possibilities for meaning’ (Moustakas 1990:28). Immersion was aided by activities in four main areas. The first was watching film depictions of ‘schizophrenia’ (both documentary and fiction), reading first person accounts, and reading research associated with the phenomenon. The second involved creative enquiry, which comprised the on-going process of developing and filming Cotton (2010) and listening to the feedback of those with the diagnosis at screenings. Writing the screenplay that dramatised the events of Kingsley Hall was another strand of creative enquiry, and explored ethical and moral issues surrounding the treatment of ‘schizophrenia’. The third was using my own work experiences to think more about these ethical and moral issues. For example, I sometimes had to participate in a care team’s decision to enforce a client’s compliance with medication, despite my ideological discomfort. The fourth area

involved exploring experiences of breakdown and hospitalisation in my own psychotherapy, and attempting to access the unconscious “psychotic domain” (Alanen 2009:6) that emerged in that earlier experience. In going back and forth between these areas of immersion ‘possibilities for meaning’ were kept open both during the early stages of developing the research question, and then later during the data analysis stage.

Incubation

After formulating the research question there was a period of disengagement from immersive activity, in order to facilitate an ‘expansion of knowledge... on levels outside... immediate awareness’ (Moustakas 1990:28-29). During this phase, while continuing to work in the settings described above, conscious attention was directed away from the research question (p28). Moustakas likens this phase to the lost house key that cannot be found with a conscious effort to retrieve it (p28). Through the incubation of tacit knowledge, subsidiary and focal aspects of phenomenon may have been brought together to produce a ‘creative awareness’ (p29). One example of this process occurred in a later stage of the study, when time was taken out to work on a book chapter that was related to the research here. While my attention was focussed on a connected, but distinct issue to the issues explored here, the significance of meaning in experiences of breakdown and recovery became clearer, and more detailed.

Illumination

This was the fruit of the incubation phase, in which tacit knowledge may have emerged into ‘consciousness awareness’ - akin to ‘looking again’ with fresh eyes

(Moustakas 1990:29) – and led to the ‘disclosure of new meanings’ and ‘corrections of distorted understandings’ (*ibid.*). For example, during the procedures of data analysis, periods of immersion and not consciously ‘striving’ (*ibid.*) to understand the experience helped create the conditions for this looking again. This vectoring back and forth between immersion, incubation and illumination, many times over, facilitated movement between ‘subsidiary’ and ‘focal’ awareness of the experience (Gill 2000:35). This aided seeing meanings from different angles, becoming more aware of my own ‘indwelled’ frame of reference, and appreciating in what ways this was distinct from the meanings I was attempting to understand. To continue the example above, meaning *itself* was revealed to be the most significant theme. In particular, there was a realisation of the complex relationship between ‘symptoms’ and the traumatic life experiences they seemed to express.

Explication

This phase drew on the concepts of ‘focussing’ (Gendlin 1978) and ‘indwelling’ (Polanyi 2009) and self-dialogue to examine in more detail what had ‘awakened in consciousness’ (Moustakas 1990:31) during the illumination phase. This enabled ‘discovering nuances, textures and constituents’ of the phenomenon (*ibid.*). To continue the example, participants’ confusion about the meaning of their experiences seemed to produce an enormous amount of anxiety, and this led to a greater appreciation of why addressing meaning might help to reduce anxiety. In articulating these ‘angles’ and ‘textures’ a ‘comprehensive depiction of the core... themes’ (*ibid.*) emerged, and this unfolded naturally as a chronological, multi-perspective depiction of childhood, breakdown, treatment and recovery when all eight data sets were

brought together as one. A more detailed awareness of how meaning was *treated* in treatment itself then came about.

Creative synthesis

This final heuristic phase is also the final procedure of data analysis, which is described in the next chapter. However, so we can follow the continuity of the underlying phases to their conclusion, a brief overview follows. In this phase conscious attention was averted from the knowledge accumulated during the previous phases, to ‘permit an inward life of the question to grow’ (Moustakas 1990:32). The aim was to facilitate ‘a comprehensive expression of the essences of the phenomenon’ to be realised in a creative form (*ibid.*). The creative synthesis *procedure* that closes the next chapter attempts to draw together the participants’ experiences with a distillation of what had been learned on this ‘quest’. The form taken is a metaphorical narrative in which the participants’ embodied experiences are likened to a physical environmental.

5.3. Participant selection

This section details the number of participants sought, inclusion and exclusion criteria, recruitment, sampling methods, final participant population, and potential benefits of taking part in the study. Ethical issues are discussed in both this section and the next.

Number of participants sought

It is possible to conduct a heuristic study with ‘only one participant’ or ‘perhaps as many as to 10 to 15’ (Moustakas 1990:47). A median of eight was decided on. It was

hoped that with interviews lasting up to 2.5 hours, this number would provide a good degree of detail about the phenomenon researched, while also providing enough contrasting experiences to construct a rich, multi-perspective composite depiction of the phenomenon.

Inclusion and exclusion criteria, and ethical issues

Participants were sought who had experienced psychotherapy (all modalities, and including counselling, clinical psychology and its affiliates, and psychiatry where there was a talking therapy aspect to the treatment) after receipt of a 'schizophrenia' diagnosis. Other criteria were sampling issues (detailed below) and ethical considerations. Given the epistemological, ontological and methodological issues raised in earlier chapters these ethical considerations raise complex question, which require some attention.

Shore's (2006) ethical guidelines for carrying out medical research involving those with a 'schizophrenia' diagnosis point out the special consideration required for "mentally disturbed persons" who "are likely to be vulnerable" (p1). This guideline is problematic, because, as we have seen in earlier chapters, the assumption that those with the diagnosis are inherently disturbed and vulnerable is both erroneous and demeaning. Questioning whether a participant could give 'fully informed' consent rests on a similar assumption that those with the diagnosis do not possess the self-agency required to give their *own* consent. While perhaps well intended, these assumptions tend to arise from a framework of medical meaning by which those with the diagnosis can often feel oppressed (Romme *et al* 2009).

This tension noted, it was also recognised that taking part in a study which may involve exploring difficult experiences could be unsettling. It was important, therefore, to strike a balance between considering participants' emotional wellbeing, and not patronising them. In both senses then, it was important to extend the ethic of 'the treatment is the way we treat people' (Cotton 2008) to the 'treatment of the research participants and their experiences as well' (Cotton & Loewenthal 2011:87).

It was decided that a peer support perspective would provide the most appropriate guidance on this matter. Rachel Waddingham, Project Manager for HVN London, wrote to me advising that through taking part in a support group such as HVN, potential participants would have already spoken openly about, and reflected on, their experiences, and so would feel more comfortable with exploring them in an interview than someone who had not. With regard to informed consent, it was felt the attempt to make judgements about this would risk patronising potential participants, and so consent given should be taken as fully informed. Finally, it was suggested involvement in a peer support network would provide a space to reflect on participation. This advice can be found in full in the appendix.

Following this advice, it was decided that potential participants should be drawn from three peer support networks: HVN, the National Survivor User Network (NSUN) and Intervoice (IV). IV is an online forum managed by HNV, so IV's agreement to participate was covered by HVN's participation²¹.

²¹ An overview of all three organisations, along with letters confirming the suitability of members of HVN and NSUN for participation can be found in the appendix.

With this framework in place, it was decided that if a potential participant might be too unsettled by the requirements of participation, they should not be included. This was determined by discussing the aims of the research on the telephone with potential participants, along with issues of consent and anonymity. If there was cause for concern from either myself, or the potential participant, this was to be discussed with both the relevant peer support network and my supervisors. However, in the event, no such concerns were raised, and no potential participants were excluded on this basis.

Sampling

Moustakas (1990) advises heuristic researchers to identify ‘a set of criteria’ such as ‘ability to articulate experience, cooperation, interest.... Degree of involvement’ (p46). However, no further sampling guidelines are provided. Silverman (2005) suggests that a research sample should represent a slice of a wider population, which provides access to underlying generalisable principles (p126). However, the assumption that there might be a generalising principle underlying the experience researched here, in the manner put forward by Ayer for example, has been noted in previous chapters to be problematic. There were, however, three areas that Silverman helped to define.

The first concerned a ‘purposive’ dimension, in terms of the ‘parameters of the population’ that would ‘illustrate’ what was being researched (Silverman 2005:129), and this was determined by the inclusion and exclusion criteria. The second concerned a ‘theoretical’ dimension, in terms of how the ‘unit’ researched was conceptualised (Silverman gives examples of a unit as an organisation, a location, or a ‘conversation’, [p130]), and how knowledge might be accessed from it (pp131-134).

For example, the research question was deliberately broad, in order to provide a framework for discovery through intimate, free-ranging discussion. Although no specific hypothesis prefigured this question, one could say that a broad underlying ‘theory’ was that ‘symptoms’ might be personally meaningful, and more detail was sought in relation to how psychotherapy might help, or not. The third area concerned ‘access’ to the ‘unit’ (p127) containing knowledge about the phenomenon, which, like the first area, was determined by inclusion and exclusion criteria. Silverman (2005) notes that ultimately, ‘the crucial issue’ in sampling is to think through ‘one’s theoretical priorities’ (p136), and this process can be seen in previous chapters.

Recruitment method

Once the research had been approved by the Roehampton Ethics Board²², the primary recruitment route took the form of distributing information about the study to three participating peer support organisations: HVN, NSUN and IV. A secondary recruitment route involved word of mouth, through contacts made while working on Cotton (2010) and subsequent screenings of the film. This ‘snowballing’ approach is an approved recruitment path from ‘the relevant population’ McLeod (2003:30).

Potential participants were assured that any services received from participating organisations would not be altered by taking part in the study. They were then supplied with briefing information and consent forms²³, and given the opportunity to withdraw if, on further reflection, they did not feel comfortable with the conditions of the study.

²² A copy of written approval from the Roehampton University Ethics Committee can be found in the appendix.

²³ Sample briefing and consent forms can be found in the appendix.

Final participant population

From the primary recruitment route, two potential participants contacted me after reading information distributed by participating organisations. After initial telephone conversations with both, one decided not to proceed and the other (B) became a participant. A renewed circulation of information failed to draw more respondents. However, the secondary recruitment route yielded six further participants (A,C,D,E,F,G), which perhaps reflects the degree of trust participants needed to have in me in order to proceed. The final participant recruited (H), expressed an interest in taking part following a presentation of the initial findings.

All eight participants had received a ‘schizophrenia’ diagnosis, had been hospitalised at some stage, and had taken antipsychotic medication. Most participants had received other psychiatric diagnoses, such as Schizoaffective Disorder (APA 2005:319), BPD (APA 2005:706), and Dissociative Identity Disorder (DID) (APA 2005:526). For some participants, these diagnoses ran concurrently with their ‘schizophrenia’ diagnosis. All participants, with the exception of (E), were engaged in psychotherapy at the time of interview. Biographies for all participants can be found at the start of the individual depictions and exemplary portraits (Moustakas 1990:52) supplied in the appendix.

Potential benefits of participation

It was hoped that participants would be helped to reflect on their experiences without the framework of psychotherapy or other formal treatment structures and their associated agendas. This aspiration was confirmed by a number of participants who mentioned spontaneously at the end of interviews that reflecting on their experiences had been thought-provoking and helpful.

5.4. Data collection

This section details the structure of interviews, materials used, methods of transcription, coding and anonymity, and conditions of withdrawal from the study.

Interview location

Lone researcher safety was considered prior to interviews taking place. As noted in 5.3., the assumption that this participant population may suffer ‘disturbance’, and may thereby place the lone researcher at greater risk, is problematic. These issues were discussed with HVN and NSUN, and it was decided that if each made a room available for interviews where staff might be on hand should support be needed, then the issue of safety would be satisfied without causing offence²⁴. However, in the event, (A,B,C,D,E,F,G) preferred to be interviewed at home, and (H)’s preferred location was Roehampton University. These preferences were discussed with the relevant participating organisation and my supervisors, who both approved. It was agreed that my supervisors would be notified of all interview times.

Structure of interviews

An ‘informal conversational’ interview approach was used, in which ‘spontaneous questions’ were asked in an ‘unfolding dialogue’ (Patton *in* Moustakas 1990:47). This allowed for a ‘personal responsiveness and involvement’ on my part, as opposed to the hierarchical dynamic of a traditional detached, objective standardised interview (Oakley *in* Mishler, 1991:31). Silverman (2005) notes that this open-ended approach to interviews usually involves ‘intimate’ contact with research subjects and characterises Gubrium & Holstein’s (1997) ‘Emotionalism’ idiom of researching experience (p112). ‘Responsiveness’ on my behalf included self-disclosure, which

²⁴ HVN’s advice on this issue can be found in their written guidance in the appendix.

may elicit ‘richer, fuller, more comprehensive depictions from the co-researcher’ (Moustakas 1990:47). The only standardised question was the research question itself, which was read at the start of each interview and served as a containment framework for the conversation that followed. Examples of other spontaneous questions within this framework were: ‘What is your diagnosis?’ and ‘What was happening in your life that led to being diagnosed?’²⁵

This structure allowed myself and participants to be ‘caught up in the phenomenon being discussed’ (Weber *in* Moustakas 1990:48), and resulted in a free-ranging exploration of participants’ life experiences, from childhood and adolescence, the events that led to being diagnosed with ‘schizophrenia’, psychiatric treatment, psychotherapy and recovery. However, while allowing to myself to be ‘caught up’, I remained acutely aware of the potentially detrimental use of ‘therapeutic skills to extract information from participants without them personally realising what they were letting themselves in for’ (Loewenthal 2007:10).

This exploration covered the areas of questioning that Moustakas (1990) recommends (p48), and questions varied spontaneously from one interview to the next. Interviews were not ‘ruled by the clock but by inner experiential time’ (p46), and varied between a minimum of 1.5 hours and a maximum of 2.5 hours. Two interviews (C,D) were felt to require additional time, so a second sitting was arranged.

Participants were asked to terminate the interview at any time if they felt we were touching on issues that they did not wish to explore.

²⁵ (C)’s interview transcript is included in the appendix as an example of this interview approach.

Post-interview debriefing and reflection

At the close of interviews participants were offered space to reflect on what had been discussed. They were given debriefing forms, which contained information about finding a therapist and support services provided by HVN, NSUN and IV should a more comprehensive level of support be required²⁶. However, because most participants were in long-term psychotherapy already, and/or were members of HVN, none felt the need to explore this further.

Materials

A battery operated Edirol R-09 MP3 recorder was used for all interviews. Interviews were transcribed on a computer using a word processing programme.

Transcription

Interviews were initially transcribed by myself. However, due to the large volume of data (15.5 hours/140,000 words), assistance was provided by a professional transcriber, who was made aware of the confidential nature of the study. In order to minimise variance in transcription style, she was provided with transcription rules²⁷. Her transcriptions were then checked against the original recordings, and corrections made where needed. Once each transcription was felt to be an accurate representation of the interview, each paragraph was coded and numbered. All original recordings were destroyed after the study was completed.

²⁶ A sample debriefing form can be found in the appendix.

²⁷ A more detailed description of these transcription rules can be found in the appendix.

Anonymity

All participants wished to take part in the study anonymously. In order to preserve anonymity participants were supplied with ID numbers for future reference and contact at the start of the study. These ID numbers remain in the findings chapter. Other potential identifying data, such as places and names were also anonymised.

Coding

Because of the large volume of data, it was necessary to code verbatim with participant ID, paragraph number and line number, for example, (D:38:2). This coding system has been retained in the findings (Chapter 6) and the discussion (Chapter 7), and can be cross-referenced with examples of an interview, individual depictions and exemplary portraits provided in the appendix. Moustakas (1990) does not supply guidelines on coding.

Withdrawal from study

Participants were advised that they could withdraw from the study at any time prior to their data being written up. The deadline given for withdrawal was August 2012. However, no participants chose to withdraw from the study.

5.5. Conclusion

In this chapter we saw how the aims and objectives in this study led to a method for carrying them out. This method was guided by Moustakas' (1990) six 'phases of heuristic research', which drew on the heuristic 'concepts' and 'processes' that were detailed in the last chapter. The method for participant selection and other practical issues were described, and ethical issues discussed. Where relevant, these were related

back to issues raised in earlier chapters. Where additional guidance for carrying out this method was needed, for example, in participant selection, texts such as McLeod (2001) and Silverman (2005) were referred to. The eight ‘procedures’ of data analysis (Moustakas 1990:51-52) that followed are described in the next chapter, along with the findings that were derived from them.

Chapter 6

Data analysis and findings

6.1. Introduction

Now that the method used to carry out the empirical aims in this study has been detailed (Chapter 5), along with how this method came about (Chapter 4), we can see how this method was used to analyse the resultant data and to arrive at the findings. The chapter begins with a description of how Moustakas' (1990) eight-step 'Procedures for Analysis of Data' (Moustakas 1990:51-52) were used (p54), so the reader has a sense of how this process led to the findings that follow (section 6.3. onwards).

Moustakas (1990) suggests that heuristic findings include examples of the 'core procedural steps of analysis', which are the 'composite depiction', 'individual depictions' (an unspecified number) and 'two or three exemplary portraits' (p54). However, this structure is offered as just 'one way' (p53), and it is recognised that in general 'there is no exclusive list that would be appropriate for every heuristic investigation' (p43). The findings presented in this chapter focus on the composite depiction, which shows the 'the core meanings of... the group as a whole' (p52). This composite depiction (6.3.) is shown as a multi-perspective chronology, starting with experiences of trauma, and then breakdown, treatment, and recovery. Sections of this 'storyline' structure (McLeod 2003:145) are then illustrated with individual depictions and exemplary portraits. A detailed rationale for this approach can be found in 6.2. The findings end with a creative synthesis (6.4.), which was 'an original integration of the material that reflects the researcher's intuition, imagination, and personal knowledge of meanings and essences of the experience' (Moustakas 1990:50).

While it is hoped that these findings do not use the participants' experience as 'evidence' (Laing 1967:16), the possibility that they are being used to play 'the empirical support game' (Winter 2006:5) all the same is acknowledged. Because these issues are an important aspect of the knowledge explored in this study, they are discussed in more detail in Chapter 7, along with a wider discussion of the social and professional implications of the findings (Moustakas 1990:54). Finally, rather than the chapter concluding with an evaluation of content (as with other chapters), a critical evaluation of the study as a whole can also be found in Chapter 7.

6.2. Data analysis

This section details each of the eight 'procedures' for data analysis (Moustakas 1990:51-52), and where relevant, the six phases of heuristic research (pp27-32) and the method's underlying 'concepts' and 'processes' (pp15-27) are referred to. Where additional structure was required McLeod's (2003) guidance for 'analysing qualitative texts' (pp140-147) was referred to. Given that data collection had involved being passionately 'caught up' in conversation (Weber *in* Moustakas 1990:48), it was particularly important to not become 'the researcher who knows' once alone with the data. Attempting at all times to not lose sight of the 'frame of reference of the experiencing person' (p39) was therefore vital. Correspondingly, there was an attempt to be faithful to the participants' own language, because this articulated their 'world' and their 'way of being in it' (Laing 1965:25) better than 'technical' language. It should be noted that while terms such as 'schizophrenia' and 'symptoms' were held in contention by some participants this was not universal and so inverted commas around such terms are not used in this chapter.

So the reader can follow a complete example of how procedures of data analysis led to the findings, extracts of participant (C)'s data are used to illustrate this section. (C)'s data can then be followed throughout the findings section in the composite depiction, and in the both the individual depictions and the exemplary portraits that are used to illustrate it. (C)'s data in its entirety can be found in the appendix. Also to be found in the appendix are individual depictions for (A,B,D,E,F,H), and (G)'s exemplary portrait. This enables the reader both to cross-reference all codings back to their verbatim, and to see each participant's story in summarised form. It is hoped this also helps to mitigate against the potentially depersonalising effect of anonymised codings.

1) Synthesis of data

Audio recordings of interviews were transferred to MP3 audio files on a computer and played back. Initial thoughts were recorded; for example, I was struck by the number of differing, sometimes conflicting, diagnoses that (C) had received. After this playback, transcription began, and the rules governing this were detailed in Chapter 5.

2) Immersion in data

Once interviews had been transcribed, reading and re-reading allowed for 'timeless immersion', in which knowledge about both the whole and the detail of the experience emerged (Moustakas 1990:51). For example, beginning to understand the wider picture of (C)'s life story enabled an understanding of the details that emerged in her psychotic experiences, such as the alien she saw (C:44:2). This detail then helped with an understanding of her wider story. Initial themes that emerged at this

stage were noted down on the transcript, for example, how voices often represented experiences of abuse (C:37:6).

3) Setting aside data and creating an individual depiction

An interval of rest followed this intense immersion. This allowed for a period of ‘incubation’ (Moustakas 1990:28-29) and a growing tacit awareness of qualities and themes. In one sense of course it is impossible to say what tacit awareness was stimulated, because this awareness can only make itself apparent when it becomes explicit. However, it seemed that with this approach there was a greater openness to meanings that revealed themselves - the ‘illumination’ that Moustakas refers to (pp29-30) - rather than anxiously trying to find ‘answers’. McLeod (2003) likens this kind of process to an ‘unfreezing’ of a previous ‘fore-understanding’ of meaning and allows for ‘the opportunity for discovery’ (p144); a process that reminded me of the importance that Heidegger places on possibility. An example of this was how experiences such as making Cotton (2010) formed a ‘fore-understanding’ in which the meaningfulness of symptoms seemed a given. By drawing on phases of incubation and illumination after immersion in (C)’s data, returning to this data I became aware of the deeper significance of meaning in her experiences. This new awareness guided the creation of an individual depiction of ‘the qualities and themes’ (Moustakas 1990:51) that encompassed (C)’s experience.

Moustakas (1990, 1994) does not offer detail or examples of how themes should be arrived at. McLeod (2003) recommends breaking texts into ‘discrete meaning units... whose meaning and properties can be closely examined’ (pp142-143). Each of these units was given a descriptive heading, for example ‘early life experience’, and then all

related units were grouped together²⁸. It was then possible to look more closely at themes within each unit, which were summarised descriptively. For example, **Experienced a first phase of trauma in childhood**, which contained the verbatim (C:34:11-13) and (C:70:3-7)²⁹, and **Early way of coping with trauma was to suppress it**, which contained (C:44:1-4).

Where several themes seemed close in meaning, they were reduced to a single theme. This sometimes reframed the overall meaning. For example, feeling powerless in treatment relationships was initially represented by the themes, **Therapist not reflecting on their power felt disabling** (C:104:12-14) and **Participant struggles with power relationships in therapy** (C:13:1-6). This seemed better represented by the theme **Not voicing personal feelings about therapist often brought therapy to an end and was unhelpful**.

Themes were then illustrated with a piece of edited verbatim that best represented it. Sometimes a theme was best illustrated by a number of sub-themes. For example, with the example of the last theme mentioned above, the following sub-themes were used: Gender of experienced psychoanalytic psychotherapist and layout of the room provoked past trauma which participant felt unable to discuss (C:23:1-11), Participant felt DID therapist was inflexible at times and couldn't admit to being wrong (C:146:5-C:147:7), Unspoken power dynamics in therapy brought up memories of abuse (C:13:5-9). During on-going periods of immersion, incubation, illumination and explication, themes and sub-themes were reduced as far as possible, without losing their descriptive quality or distinctiveness, and repeatedly checked against the data to

²⁸ An extract of (C)'s interview transcript, which has been broken down into 'meaning units' and annotated in this fashion can be found in the appendix.

²⁹ Themes are shown in the same bold format in the findings so the reader can follow the continuity more easily. Similarly, sub-themes use the same underlined format.

ensure they remained representative. Once themes could not be further reduced, verbatim was edited to represent each theme (if stand alone), or each themes' sub-theme. For example:

Unspoken power dynamics in therapy brought up memories of abuse

(C:13:5) I'm used to having psychiatrists that can section me and give me medication and not challenging and be very passive within that for fear – that's my childhood, and that's where it is now. So in therapy I would do things like I wouldn't ask to use the toilet, 'cos it's a horrible boundary cross for me to use the bathroom in the therapist's house...

Reviewing all of these 'meaning units' together, it was not clear how best to organise them into a finished individual depiction. For example, should (C)'s childhood experiences be represented in experiences of psychotherapy that were considered helpful, because it was through this that (C) seemed able to reflect on her experiences of trauma? Or would a section that detailed experiences of trauma at different stages of life that were grouped together in one section be better? Moustakas (1990) gives Clark, J's (1988) visual 'map' of 'core themes and patterns' as they 'began to emerge and take shape' (p49) as one example of a method for gathering themes together. This approach was useful, but it did not reveal an organising principle.

McLeod (2003) suggests that composing a 'narrative summary' of each interview can be helpful (p142). After writing a summary of (C)'s experiences as a one-page biography, it became clear that a life story chronology would be a helpful way of presenting the overall depiction. McLeod also notes there are 'advantages in writing up qualitative research from a series of thematic perspectives following different storylines' (p145). With the growing significance of meaning in breakdown and

recovery in mind, the meaningfulness of symptoms became the main ‘storyline’, and the life story chronology seemed an effective way of depicting this. Using this ‘storyline’, themes were then placed into groupings. For example,

C1) Participant experienced trauma before diagnosis of schizophrenia

C2) Psychotic symptoms appeared in late adolescence/early adulthood

C3) Initial contact with mental health services was not helpful

C4) The psychiatric system of diagnosis is problematic

C5) The psychiatric system of diagnosis was more helpful when it took participant’s wishes into account

C6) The first phase of recovery started when participant’s experiences were taken seriously

C7) When psychotherapy has been unhelpful

C8) When psychotherapy has been helpful

C9) Voices and personalities have a meaning that needs to be understood

C10) Coming off medication was necessary to further recovery

C11) Statutory mental health services are structured in a way that does not meet people's needs

The 'narrative summary' of each participant's experience of the phenomenon was then added to the start of their individual depiction. The aim was to give the reader a glimpse of the 'focal' aspect of the experience (Moustakas 1990:24) at the start before going on to the 'subsidiary' detail' (*ibid.*) of themes illustrated with verbatim.

4) Checking individual depictions against original data.

Continuing with the example of (C), the individual depiction was checked again against the original interview. Sometimes, during this process, my thematic description needed to be adjusted and/or the accompanying verbatim was edited further for a more focussed illustration of a theme.

5) Steps 1 to 4 repeated for each interview

Procedures 1 to 4 were repeated with each participant's data. Each depiction followed the life chronology and meaning 'storyline' presentation that was described above. In allowing for phases of immersion, incubation, illumination and explication for each data set, this process took several months to complete.

6) Composite depiction

The aim of this depiction was to bring together the group experience in a 'vital and unified manner', in a form that included 'all the core meanings of the phenomenon as experienced by the individual participants and the group as a whole' (Moustakas 1990:52). After reviewing all of the individual depictions together, the meaning

‘storyline’ and its life chronology form seemed the most effective way of furthering this aim. Several attempts were made to represent all themes together in the style of Clark, J’s (1988) map. However, there were too many themes. After a pause to step back and allow incubation to take place, a fresh approach presented itself. In this, the chronological thematic grouping titles were taken from each participant, and placed together. Seen together in overview, it was then possible to reduce each grouping down to a core ‘meaning unit’. For example, by placing thematic grouping **C1) Participant experienced trauma before diagnosis of schizophrenia** beside **E1) Participant experienced trauma in childhood** and **D1) Experienced a traumatic childhood** it became clear that all three could be reduced to one thematic grouping for the whole group (denoted by TG), as follows:

TGi) Life experience and breakdown³⁰

A similar process followed for each major stage of the chronology, which became the following thematic groupings:

TGii) Inpatient and residential treatment

TGiii) Psychotherapy that was unhelpful

TGiv) Psychotherapy that was helpful

TGv) Recovery

³⁰ Roman numerals are used here in order not to confuse thematic groupings with the numbering system used for constituent themes shown in the composite depiction.

Themes from individual depictions were then incorporated into thematic groupings to give a group depiction, and then sub themes and verbatim were added where they helped to describe each theme in the round. The resultant group depiction was over 30,000 words, and needed to be significantly reduced. This was achieved by writing a ‘narrative summary’ (McLeod (2003:142) of every theme, in the manner used for individual depictions. This summary was then checked against the un-summarised version to make sure all the core themes and meanings had been included. Where a theme seemed important but not shared, for example, (H) was not sure if Electro Convulsive Treatment (ECT) had been helpful or not (H:3:9), this was discussed in the summary. This summary then comprised the finished composite depiction, and is similar in structure to both Atkins & Loewenthal (2004) and Schultz’s (1983) composite depictions, the latter of which Moustakas (1990) uses as an example (pp70-71).

Extracts from individual depictions were then added to this structure in **TGiii)** and **TGiv)** to illustrate the group experience in more detail, because in these groupings participants reflected on the meaningfulness of their experience as a whole through the ‘focal’ (Moustakas 1990:24) prism of their psychotherapeutic experiences. Finally, extracts from individual depictions and two exemplary portraits (C,G) were used to illustrate **TGv)**, in which participants reflected in a similar fashion through the ‘focal’ prism of recovery as a whole.³¹ It is hoped that this structure represents the group experience in a ‘vital and unified manner’ (p52), while not losing the ‘essence of the person’ (p39), and helps to connect the ‘subsidiary’ (p24) details of individual experiences with the ‘focal’ aspects of the experience for the group as a whole.

³¹ It was not always clear whether this meaningfulness was attributable to psychotherapy, to other recovery process, or a combination of the two. Where the distinction was not clear, the attribution was made to recovery as a whole. However, inevitably there may be some blurring between the two.

This overall presentation structure may say something about my own ‘search’, and the attempt to understand my own experiences in greater depth. As such, while the first person has not been used to summarise individual depictions or the composite depiction in the manner of some of the examples given by Moustakas (pp60-85), the ‘thoughts and analysis the researcher has had during the heuristic process and new meanings derived from this’ are present (Atkins & Loewenthal 2004:504) throughout.

7) Exemplary portraits

Completing the composite depiction involved a constant process of arranging and re-appraising themes. Several times the choice of potential portraits, that could exemplify both the group and retain a sense of the individual (Moustakas 1990:52), changed. The life chronology and meaning ‘storyline’, that was arrived at in the final composite depiction, seemed best exemplified by (C) and (G), who offered ‘the most complete picture of the experience’ (Atkins & Loewenthal 2004:497). In order to retain the continuity of the composite depiction that each portrait exemplified, its five thematic groupings were retained. Each grouping was then illustrated with extracts of biographical summaries, themes, sub-themes and verbatim taken from (C) and (G)’s individual depictions. Each portrait was then completed with a short biography that focussed this time on the ‘focal’ prism of psychotherapeutic experiences, so that a response to the original research question was exemplified at the same time. This structure is similar to Rodriguez’s (1985) exemplary portrait, which Moustakas (1990) uses as an example (pp76-78).

8) Creative synthesis

Heuristic research demands the researcher go through repeated phases of immersion, incubation, illumination and explication, where dimensions of tacit and personal knowledge are accessed, in order to gain a greater knowledge of the phenomenon. This final data analysis procedure *and* heuristic phase, involved ‘an original integration’ of this knowledge (Moustakas 1990:24), at the same time as being ‘peak moment’ in the researcher’s ‘self-understanding’ (p90). The creative synthesis presented at the end of this chapter explicates this ‘peak moment’ in ‘an aesthetic rendition of the themes and essential meanings of the phenomenon’ (p52), in a form that retains the life chronology and meaning ‘storyline’ used in procedures 3, 6 and 7.

Moustakas notes that the heuristic ‘researcher as scientist-artist’ ethos (*ibid.*) is more important than the actual form taken for the creative synthesis, which the researcher has a ‘wide range of freedom in characterizing’ (p52). While this ‘usually takes the form of a narrative depiction utilizing verbatim material and examples... it may also be expressed as a poem, story, drawing, painting, or by some other creative form’ (p32). A summarising descriptive narrative form is used here, in which the participants’ embodied experiences are likened to a physical environment. This form is similar to Hawka (1986), one of the examples given by Moustakas (1990:85-86).

6.3. Composite depiction

In the composite depiction that follows, each thematic grouping starts with a short summary and a piece of illustrative verbatim, prior to the depiction of individual themes.

6.3.1. TGi) Life experience and breakdown

This grouping follows a rough chronology from early life experiences to breakdown somewhere between late teens and early twenties. The experience of trauma was a theme that dominated this grouping.

(D:16:1) I think the whole problem, the reason why I got the diagnosis of paranoid schizophrenia was the fact that I was escaping from a life that I was born into... (D:16:7) [I]f I didn't actually break out from my... mental confine, and the social aspects of my life at the time, I would have committed suicide.

1) Experience of trauma in childhood

All participants talked about traumatic experiences in their childhood. Often, this began with difficult parental relationships, or tense home environments (A,B,D,F,G,H). Maternal relations were often felt to lack loving expression (A,D,F,G,H), or were characterised by the experience of being controlled (A,D,F,H). Less often, difficult paternal relationships were experienced (D,G). There was also sometimes a *lack* of parental relationship (A,B,F), which left participants feeling isolated and struggling to communicate. At this early, stage, some participants felt themselves already being labelled as the family “problem”³² (A,D).

Feelings of inwardness and insecurity were apparent from an early age, and seemed to erode the potential for a firm foundation which might support difficulties in later childhood. These included being bullied at school (A,B,D,E,F,H), sexual abuse (C,E,G) and physical and psychological abuse (D,G,H). These experiences seemed exacerbated by a lack of secure relationships at home within which to address them,

³² Double inverted commas are used where a concept is summarised, rather than actual verbatim.

and reinforced by early internalised messages, such as “I am not loveable” (F), “I am a monster” (C), and “I am mad” (D).

2) Confusion as issues deepened when not addressed

All participants talked about becoming increasingly confused and disorientated during childhood and early adolescence. Unable to speak about what was troubling them, there seemed to be a retreat inward as a way of dealing with feelings of vulnerability, insecurity and anxiety. Struggling to manage complex and often frightening feelings, all participants spoke about developing coping mechanisms that protected them from traumatic feelings, but which also further alienated them from the outside world. For example, burying earlier experiences (C,E,F,G,H), and creating a split between inner, private self and outer, public self (B,C,D,F,G).

Increasingly, there were difficulties with self-esteem and confidence (A,B,F), feeling unable to become their own person (D,H), or having to conform to social or parental pressure to be someone they felt they were not (B,D,H). Several participants started to feel deep confusion and guilt about their sexual identity (B,D,F). Wishing to be someone else or to escape their life was one attempt at finding relief (B,D), while others found that self-harm (E,G,H), alcohol and drugs (A,D,F), or obsessive rituals (G,H), could be used to try and manage painful internal worlds.

3) Experience of trauma in adolescence/early adulthood

The majority of participants experienced a second trauma in later adolescence or early adulthood, often within the first two years of university or working life. This included being raped (C,E,F,G), experiencing relationship breakdown (A,E,F) being bullied

(D,F,G,H), attempting suicide (H), parental divorce (A), and the pressures of early adult life (A,B,D,F,G,H). This second experience of trauma often cut deep into buried earlier experiences, and intensified existing feelings of hopelessness, lack of self-worth, depression and anxiety.

4) First appearance of psychosis

While most participants had experiences of depression and anxiety throughout childhood and adolescence, and some of them had sought treatment for this (C,E,H), psychotic symptoms such as hearing voices tended to appear only after the experience of a second trauma. (C,F,G) however, had first heard voices in childhood.

5) First attempts to get treatment did not address underlying issues

The first attempt to get treatment was mostly unsuccessful; either because participants were thought not sufficiently unwell to be hospitalised (B), or because treatment principally took the form of medication, and this did not address the issues underlying symptoms (A,C,D,E,H).

6) Experienced breakdown

Breakdown swiftly followed this second phase of traumatic experience because it seemed there was no longer any internal resource, such as ‘burying’ (H), or ‘splitting’ (G) to call upon. For (A,B,C,E,F,G) breakdown started with hearing one voice. For (G) this first voice seemed to represent an angry side of herself that she couldn’t express by other means, and was initially welcomed. For some, the initial voice was frightening and sounded like, for example, the voice of an abuser (C,E) or bully (F). For others, the voice took the form of a metaphorical malevolent figure such as the

devil (B), or evolved into something more particular to their own situation but equally malign (C,E,F,G). For (A,B,C,E,F,G) the initial voice multiplied into several voices.

Most participants were unable to speak about what they were experiencing at the time and tried to conceal it, making them feel more isolated and anxious. Trying to make sense of what they were experiencing led to developing ever more convoluted and obsessive belief systems (A,B,C,E,F,G). (D,H) heard only feint voices at times, but experienced intense feelings of paranoia which led to similar belief systems. Most participants feared that others could hear their voices. Some participants believed that recreational drugs either triggered their first voice (A), or intensified psychologically fragile states (F,D,E).

6.3.2. TGii) Inpatient and residential treatment

For all participants treatment began with diagnosis and treatment in a psychiatric hospital. For (B,C) this later included treatment in a residential TC. In the early stages, medical treatment brought with it a sense of relief that someone knew what the problem was, and how to treat it. However, this often gave way to the despairing realisation that medical treatment was unhelpful, if not actively making things worse.

(C:49:4) [The psychiatrist said] “It’s ok, we know what’s wrong with you... (C:49:5) Come into hospital, we’ll just start you on some medication and get you back out there”... (C:49:8) [It was like] “Wow, someone understands. It is me, I’m *ill*... (C:42:1) no wonder I ran to that label... because it was like... “there is something really bad underneath the surface that no one else can see”. (C:42:4) And that did so much damage...

1) Diagnosis was a relief at first, then an obstacle to recovery

Most participants were relieved at first to be told by professionals that they knew what the problem was, and how they could be helped (A,C,G,H). Often the relief was because “knowing the problem” deferred thought about deeper, more troubling issues (A,C). However, the diagnosis soon became frightening because it was felt to be a negative label (B,D,E,F) that affected others’ perception of them (B,G,H), and was used by professionals as a lens through which to interpret their behaviour (C,E,G,H). The framework of diagnosis was felt to be arbitrary, inflexible, and told you nothing about a person’s experiences (C,E,F,G,H). Some found themselves having to edit their experiences when speaking to psychiatrists, in order to fit the diagnostic model (B,C,E). This ill-fitting framework then directed treatment which ignored underlying issues (A,B,C,E,F,G,H). Some participants who challenged their diagnosis were labelled as difficult and given a BPD diagnosis (C,E), leading to the feeling that the dynamics of treatment were unwittingly mirroring the experience of being abused (C,G). Diagnosis was felt to be helpful, however, when it took the participants’ wishes into account (C).

2) Treatment in hospital and residential therapeutic community was a mixed experience

The journey through hospital and other inpatient or residential treatment facilities mirrored participants’ relationships with diagnosis. At first, hospital seemed safe (D,H). There was a camaraderie amongst patients there (F,H), as well as in a residential TC (B). However, treatment in a TC also felt rigid, un-containing and re-traumatising (C). If there had been an initial feeling of safety, this soon turned to frustration and despair for most participants, and the realisation that medical treatment

was geared toward suppression of symptoms either made things worse (C,G,H), or had to be tolerated because there was no other choice (A,D,F). (G) felt that hospital was a traumatic experience, and that she had entered it an unhappy teenager and emerged ‘a schizophrenic’. (E) also felt hospital was a traumatic environment, and (C) had similar feelings about both hospital and residential TC treatment. (D) was the only participant who felt hospital had been a good experience overall, because it was safer than prison or the community.

3) Medication has been helpful at times, but has extreme side effects, and is often counterproductive

After receiving a schizophrenia diagnosis, the principal form of treatment for all participants was medication. (A,B,C,D,F) initially felt that antipsychotic medication helped reduce their voices, and aided stability (D), but had severe side effects (A,C,D,F). These were tolerated because there seemed no alternative. (D) learned not to speak about feeling paranoid because, without consultation, his medication would be increased if he did. However, at the same time (E,F,G,H) thought that antipsychotic medication had little impact on symptoms overall, and low mood in particular. (E,F) found that self-medicating with recreational drugs and alcohol was more effective. The one participant (H) who experienced ECT felt it may have been helpful, but wasn’t sure because she could no longer remember that period of her life clearly.

4) Psychiatric treatment is more helpful when there is a good relationship with the psychiatrist

(B,F) felt that when there was a good relationship with their psychiatrist, treatment was more helpful, and where the relationship was bad treatment was unhelpful. For example, (B) felt that when he hadn't made progress, a psychiatrist would become frustrated with him and want to pass him on to someone else.

5) Not addressing underlying issues made things worse

(C,F,G,H) thought treatment that focussed on the suppression of symptoms was often counterproductive because it did not address the underlying issues that were driving symptoms. (C,G) thought this approach caused additional symptoms that then required more suppression-approach treatment. For example, (C) began lactating after being given Risperidone. She hadn't been told that this was an expected side effect, and so this seemed to be evidence of the alien that she believed was living inside her. The resultant anxiety seemed to require more medication.

6) Repeat breakdowns when underlying issues went untreated

This was experienced in a number of ways. Returning home from hospital to unchanged problems led (D,G) to spiralling paranoia, and (B) to intensifying voices and plummeting mood. For others there were additional triggers. The death of a supportive family member and becoming homeless deepened (F)'s despair and led to a suicide attempt. For (A) the break-up of a relationship coinciding with his parent's divorce escalated his drug use, which triggered more symptoms. (E) found a supportive religious order, but was rejected by them and then felt alone and surrounded by evil. All felt stigmatised by the diagnosis, and this compounded

feelings of self-loathing and the desire to isolate themselves. (H) was the only participant to not experience multiple breakdowns. (E) was the only participant to feel she had not yet addressed underlying issues, and thought this was why she was as frightened of these issues now as she had been when first diagnosed.

7) Recovery started when participants were able to take responsibility for it themselves

Recovery started for (D,G,H) when they began to draw on their internal resources. For (A,C,G,H) recovery required no longer depending on mental health services for solutions, but looking to peer support networks, such as HVN, instead. Recovery involved examining the meaning of voices and the experiences to which they related, which was painful for all. Making this link helped reduce symptoms and improved the possibility of an active working life. (A,C,D,G) realised that in order to further their recovery, they would need to explore this link in psychotherapy. (B,F,H), meanwhile, seemed to come to this realisation later in their recovery.

6.3.3. TGiii) Psychotherapy that was unhelpful

This thematic grouping and the next (TGiv) contain extracts from individual depictions. Overall, participants found psychotherapy an important part of recovery. However, there were aspects of psychotherapy that were unhelpful. It should be noted that (A,B,C,F) spoke in more detail about this than (D,E,F,H), and (G) did not speak about it at all. Unhelpful psychotherapy often mirrored the same qualities that were found to be unhelpful in psychiatric treatment.

(E:52:14) I stopped seeing [the clinical psychologist] was when he was like, “We can do this work with your voices, but you kind of have to commit to it. And you have to have some kind of expectation that it will work, or it won’t work.”

1) Not having a choice in the type of psychotherapy offered

(A,C,F) found that the only psychotherapy available from statutory mental health services was short-term CBT. (E) was offered sessions with a clinical psychologist, and (D) was offered an undisclosed modality in a secure hospital. (A) illustrated how a lack of choice seemed dispiriting:

(A:155:18) [T]he CPN gave me 7 sessions [of CBT] and then said “The NHS has nothing to offer you”... (A:156:1) Because I didn’t want CBT...

(C) had studied ‘CBT for psychosis’ and felt she knew ‘the tricks’ (C:129:10), but did not feel it would be useful. Similarly (F) found CBT ‘wasn’t of any use to me at all’ (F:146:1), and felt his therapist ‘didn’t really seem to know what she was doing’ (F:146:1). As this was all that was offered initially, (F) seemed to conclude that therapy as a whole would not be helpful; a view that persisted for several years. (E) felt her clinical psychologist ‘wasn’t prepared to keep working with me, if I wasn’t prepared to work on something’ (E:53:13). An alternative was not offered and she stopped therapy. (D) was the only participant who felt satisfied with not having a choice because ‘I took all the therapy I could find’ in hospital (D:76:1), and ‘[t]hat’s when I got on the road down to recovery’ (D:130:12).

(B) was the only participant who had a choice in what was offered by mental health services. For example, when he found he did not get on with his initial therapist, he

was offered another, who he felt helped him greatly (B:97:1). (G,H) were not offered psychotherapy by mental health services.

2) Therapy relationship did not feel safe, or secure

When the relationship did not feel safe or secure, the work often did not continue.

There are a number of sub-themes that help us to see this in the round.

Lack of human connection

(F,B) spoke about this in most detail. (F) found the psychoanalyst he worked with ‘professional and not caring’ (F:151:10). ‘I didn’t feel like he treated me like a human being. He didn’t value my pain’ (F:154:1). This made (F) feel he was being treated like a ‘thing’, which reminded him of the experience of being sexually exploited and bullied in the past (F:154:1). (B) had a similar feeling with first therapist he worked with. ‘I didn’t feel he was interested in me... I was so ill and he wasn’t asking me the right questions. He didn’t seem to have empathy with me (B:85:1-2).

(A,E,C,H) made indirect reference to this quality. For example, the CPN who gave (A) seven sessions of CBT said that the NHS had nothing more to offer him when he asked for another form of psychological therapy (A:155:16). (C) implied a similar lack of connection in all of her therapy relationships, bar her current art therapist. While (E) found her psychologist ‘sound’, the pressure to conform to his way of working, and his ‘stock psychological’ responses (E:50:22) also implied a lack of human connection.

Fear that they might be too challenging for their therapist

This sub-theme seemed a response to sensing the therapist's discomfort. (B) feared his difficulty in communicating at the time might have been too overwhelming for an inexperienced trainee therapist he worked with (B:87:2). (C) meanwhile was fearful that her therapist didn't know what to do with traumatic recollections of sexual abuse:

(C:134:19) I felt she just didn't wanna go there or couldn't go there and I think that's, yeah, I just disappeared at that point...

Fear of talking openly

(B) thought the rules of the TC he was treated in made discussing sexual feelings about other residents difficult (B:86:1). While the only participant to make explicit mention of this sub-theme, (C) inferred a similar experience. For example, her experience of both CBT (C:87:4) and psychoanalytic (C:137:6) technique closing down conversation; her fear that she was too much for inexperienced therapists (C:134:15); feeling dominated by her DID therapist's strong personality (C:146:5–147:7); and feeling unsafe with a male psychoanalyst (C:23:1-23:8), all seemed to produce a fear that she could not speak openly.

3) Therapist inflexibility

What was felt as inflexibility seemed a major obstacle and seemed to produce an overall feeling of being dominated. This aspect seemed to remind some participants of the aspects of psychiatric treatment that they had found coercive, or dominating. Three sub-themes describe different aspects of this theme.

Inflexible use of theory and technique

Experiencing an expectation to conform to a theoretical model seemed to feel domineering. For example, (C) found her DID therapist made an implicit demand to ‘attach’ to her, because that was what was supposed to happen in theory (C:151:2). In a more general way, (B) suggested the expectation to attend a weekly sessions in one to one psychotherapy felt like too much pressure (B:110:1-8).

Looking more specifically at how theory was used, (A,C,F) felt CBT was manualised and inflexible. For example, when asked to provide examples of strong reactions to her voices (C) felt compelled to fit the agenda set by the therapist for the session, and so would make up examples to please them (C:92:1):

(C:88:14) [T]here was no talking around it or kind of exploring what it meant to me – it was a conveyor belt, it just felt really prescribed.

(C) then felt that a change in her diagnosis (where BPD was added) brought about a change in the way her therapist responded to her. This involved being put ‘in a box’ in which her therapist concluded, “This is personality difficulties coming out here, this is why I feel uncomfortable and why we're not getting very far ” (C:93:8-10). (A) meanwhile, found CBT’s approach made inflexible value judgements, because:

(A:160:3-6) [I]t relies on the idea that certain thought patterns are pathological, it’s kind of telling you that you’re thinking wrong, whereas I think that the way I think is perfectly normal considering my experiences...

Feeling required to 'rearrange my thought patterns' was also felt to obstruct exploring underlying issues (A:161:1-7). (F) gave little detail about what was inflexible, but thought the assessment procedure was rigid (F:142:1). However, he also felt 'zombified on drugs at the time' (F:143:1), so found it hard to remember. (E) thought her clinical psychologist often had a 'stock psychological response' to what was discussed (E:50:22), and this seemed frustrating at times. Also feeling she needed to work in a way that her therapist wanted, or not at all (E:53:12), indicated a degree of theoretical inflexibility.

(F) found his psychoanalytic psychotherapist's 'blank screen' approach alienating (F:154:1-156:1), and the fact that this was not either picked up, or the approach adapted, suggests a degree of inflexibility. (C) found a similar inflexibility in psychoanalysis. For example, she was turned down by one psychoanalyst because she was deemed to have 'poor ego integration' (C:108:3), which felt like a rejection. Working with a trainee psychoanalytic psychotherapist later, (C) thought the repetition technique 'didn't feel very validating', and contributed to her losing confidence in the therapist (C:137:6). (C) also suggested that the technique may have been used as a way of her therapist masking a lack of confidence (C:137:6). She had similar feelings about a CBT therapist who 'didn't appear to be very confident in what she was doing' (C:89:3), and tried to work with her with the aid of a manual (C:87:4). Similarly, (F) thought his CBT therapist 'didn't really seem to know what she was doing' (F:146:1).

Feeling dominated by the therapist's personality

(C) felt dominated by her DID therapist, a pressure to conform to her agenda, and that she could not speak about the effect this had on her (C:146:5–147:7). Similarly, (A) seemed to feel dominated by the personality of the CPN providing CBT (A:141:17). In a similar vein, (H) felt the psychoanalyst she worked with in family therapy was too blunt at times, and this seemed to lead to the therapy ending prematurely (H:45:3). (D) found that in the talking therapy aspects of his work with one psychiatrist, he felt he was made to 'do things that I didn't want to do' (D:77:3), for example, reconciling with his violent, abusive father (D:78:1).

Little room to explore experiences and make sense of them

In her work with a DID therapist, (C) felt that there was not enough room for her to explore her own meanings:

(C:145:8) I felt she pushed a lot and had ideas about [what my experiences meant]...

(C:145:10) I don't want someone else telling me that this is real and to deal with that, I wanna feel that I'm making sense of it myself...

Similarly, (A) felt strongly that he wanted to explore his experiences (A:160:1) but that CBT was too rigid to allow this. This then felt like a replication of the pressure to fit into the family and school structures that had been problematic in the past (A:160:1-162:1). While (A,C) were the only two participants to speak of this quality directly, other qualities in this inflexibility theme seemed unhelpful because they also prevented exploration. This inference seems confirmed by the value placed on exploration of meaning by most participants in the next thematic grouping.

4) Lack of therapist awareness

For (C), psychiatrists who had the power to section and medicate her mirrored the abuse she suffered in her childhood (C:40:1). These fears were transferred onto her early psychotherapy relationships, and feeling unable to explore this with her therapists, perhaps because they were unaware of what was playing out between them, seemed painful (C:13:5). In another example, the psychoanalytic psychotherapist (F) felt was uncaring (F:154:1) did not seem to sense how this felt to (F) like being ‘turned into a thing by people’(F:154:2).

In other less direct examples, (E)’s clinical psychologist did not seem to sense how the pressure to commit to his way of working (E:52:15) might have led to (E) feeling paralysed (E:53:2). Similarly, (D)’s psychiatrist did not seem aware that his ‘advice’ to (D) about re-connecting with his abusive father felt like ‘he had power over me’ (D:7:10) and caused bad feeling (D:79:1).

6.3.4. TGiv) Psychotherapy that was helpful

An overarching theme throughout this grouping was how psychotherapy helped participants to explore the meaningfulness of their symptoms. For example, without having done this (C) felt she would have been unable to work or have a relationship, and that ultimately, she might not be alive (C:71:9-13). (H) summed up the overall group experience:

(H:64:3) [T]here is this attitude... “What’s the point? Medication will help them, schizophrenia isn’t a suitable thing for psychotherapy.” And I disagree with that very strongly.
(H:63:3) [If] I had that opportunity in hospital, things could have been different. I could have recovered in a different way and more quickly...

Because participants had more thoughts about what was helpful about psychotherapy than what was unhelpful, this thematic grouping contains more detail.

1) Having a choice in which psychotherapist to work with

This seemed helpful because there was less pressure to fit in with a person or modality that did not suit them, and helped participants feel they were proactive in their recovery:

(A:174:20) I chose [Lacanian psychoanalysis] on purpose because it's something I can work with. And that's me taking an active part in my therapy...

(C) found being proactive about seeking out an experienced psychoanalytic psychotherapist gave her confidence and a feeling of being in control (C:22:3-4). Being able to end the work with a therapist and to find an alternative also seemed helpful. For example, (B) found choosing an alternative to his first residential TC therapist, this time one he had a rapport with, was helpful (B:88:1-3). After working unsuccessfully with CBT and psychoanalytic therapists (F) found working with a PC therapist fruitful. Choice was not an issue for (D) initially because he 'took all the therapy I could find' (D:76:1) in secure and medium secure hospitals. However, he seemed to find having a choice in the counsellor he worked with more recently useful. While not speaking explicitly about choice (G,H) had been responsible for finding a psychotherapist themselves, and this also seemed constructive for them.

2) Some tips and techniques have been useful

(E,C) felt that some of the behavioural techniques they had learned were useful. Prior to being diagnosed with schizophrenia (C) saw a CBT therapist for anxiety and

depression, who had given her a hand-out on the ‘traps of thinking’. She continued to find these useful after being diagnosed with schizophrenia (C:95:2). (E) thought that her clinical psychologist ‘gave me some quite helpful perspectives on things that came up’ (E:50:23), although she no longer remembered what they were (E:51:4). No other participants made reference to this theme.

3) The quality of the psychotherapy relationship is important

At the most fundamental level, being able to develop a human connection with their psychotherapist seemed important. Once this connection was established, it helped some participants to feel safe, which was an important precondition for discussing traumatic experiences. Feeling liked, or valued, feeling listened to and understood, and being able to speak openly and challenge their psychotherapist, all seemed to be valuable aspects within the relationship. Four sub-themes help us look at this in more detail.

Feeling safe in the therapy relationship

This seemed an important starting point, as (C) suggests:

(C:80:10) [B]efore I build a relationship with a therapist, it takes me a long time to really feel there's some trust there, so I take a long time sussing it out... (C:78:1) I'd been so used to keeping secrets for my whole life, that the idea of talking to someone about it just seemed really alien.

One fear was that once her therapist saw past the ‘nice’ exterior, they would see ‘all this yuk that came from your childhood that will be really bad for them, they won’t be able to cope with it’ (C:43:3). Similarly (G) feared revealing the ‘undesirable aspects’

of herself associated with traumatic experiences (G:103:3), which made intimacy with another person difficult (G:103:1). (B) thought his second residential TC therapist was interested in him and respected him, which made him feel worthwhile, safe, and less frightened (B:98:1-B:100:1). Finally, (H) remembered a hidden a sense of shame about being diagnosed in the first place, and that it took her a while to speak about this with her psychoanalytic psychotherapist (H:56:4). Sensing her therapist was a ‘very safe person’ helped (H:56:8).

Developing a human connection on a more equal footing

Feeling respected by his PC therapist helped (F) develop a connection with him (F:152:1), and encouraged him to feel good about himself. For (D), it was a revelation when his therapist told him she experienced similar feelings (D:82:16). This was the start of a realisation: ‘I wasn’t mad. I was *traumatised*’ (D:82:19). (C) felt that her DID therapist being down to earth and unconventional put them on a more equal footing (C:148:13-18). (E) meanwhile, who is a psychiatric nurse, felt that being able to talk at the same level of medical knowledge with her clinical psychologist helped her to communicate and feel understood (E:52:5-10).

Feeling validated or liked by therapist helped with confidence

(F) thought of himself as a failure. Being told by his PC therapist that he must be a tough person to survive ‘20 years in the wilderness’ and multiple suicide attempts was validating and bolstered his confidence (F:85:4-10). For (B), experiencing being liked by the second trainee therapist he worked with in his residential TC was:

(B:97:1) worth³³ a million dollars. (B:97:2) [Y]ou've had so many bad experiences, because your brain was broken and your heart was broken and somebody liked you, for God's sake.

Feeling secure enough in the relationship to challenge the therapist

Most participants spoke about how aspects of their psychiatric treatment felt coercive, which had in turn mirrored past experiences of powerlessness or abuse. (A,C,G) all felt that being able to challenge what was happening in the relationship was liberating. For example, when (C) believed her DID therapist had said something disrespectful, it felt 'brilliant' to be able to challenge her as an equal (C:14:1-6). There was a jeopardy in this, because (C)'s voices reacted to what was being challenged (C:16:6). However, by exploring this:

(C:16:8) [I]'s slowly building a little bit of trust... (C:16:14) And once I can trust her we can go a bit deeper into some of the stuff.

(A) recalled that a social worker in the past whom he began a sexual relationship with made him feel like her pet project (A:126:8). When he felt treated as a pet project by his Lacanian psychoanalyst, it was helpful to speak about what this opened up for him (A:164:2-7). (G) recognised that openness would help her to be able to challenge her therapist more, because if she could be angry with him she might 'show him more aspects of myself'. In turn this would help her to feel she could be more 'authentically' herself in the relationship (G:102:2-8).

³³ Where verbatim flows on from my summary the first word is not capitalised.

4) Non-directive exploration helped participants to engage with underlying issues

(A,B,C,D,F,G,H) spoke about how they found it helpful to explore their experiences in their own time, rather than being directed to focus on certain issues. A more open and reflective, less directive, approach to the therapy was a starting point. For example, (D) found it useful when a therapist helped him:

(D:109:1) find [my] own answer. They don't put words into your mouth, they just get you thinking about stuff, maybe from a different perspective from what you're thinking. And then you come up with your own answers.

In secure hospital this exploration involved 'anything that affected me at the time', including the past, 'intimate stuff', family, relationships that were current at the time and the murder he had committed (D:82:6-9). (B) valued the psychotherapy group he attended because in it 'things bubble up inside you' of their own accord, 'and then you can work with that' (B:115:1-5).

What seemed to be useful about this open, non-directive approach was it helped participants feel that the meaning uncovered was their own, rather than imposed by someone else. For example, (C) remembered when her psychoanalytic psychotherapist mentioned that 'the person who abused me' sounded 'cold and sort of a bit alien', rather than making an explicit causal link between the sexual abuse she had experienced as a child and the alien she saw. This allowed her to come to her own conclusion (C:107:13-22). Later, working with an art therapist, she found 'just exploring it from different angles in an arty form helps me work out what I feel about it and integrate it' (C:154:1). (H) thought this kind of open exploration was the start of:

(H:49:1) a process of highlighting things that had happened in my childhood that were not necessarily that helpful for me.

Two sub-themes help us see this exploration theme in more detail now.

Therapy not being dictated by diagnosis

Earlier, we saw how psychiatric diagnosis and treatment was found oppressive at times. Not having to engage with this framework felt liberating to most participants:

(C:57:1) The good thing about therapists is they're not about to diagnose you. Especially a therapist you pay for. "She's working for me!"

(A) thought CBT was too closely associated with psychiatric diagnosis, which 'gets rid of the therapeutic relationship' (A:14:1). In not having to engage with diagnosis on any level in the seven years he worked with a counsellor (A) found:

(A:130:2) I would talk about the voices sometimes, but only if it was related to the problems and relationships that I was having people in my life.

In (G)'s work with a psychoanalytic psychotherapist 'we spent relatively little time talking about the voices but a *lot* of time talking about me and the way I sort of feel about myself (G:108:4). Similarly, in the first six months of her work with a psychoanalytic psychotherapist, (H) talked about her relationship with her mother '[a]nd just how she couldn't let me be myself' (H:21:6), but nothing about her diagnosis. While (B,D,E,F) did not speak directly about this sub-theme, the oppressive feelings they attributed to treatment that was dictated by diagnosis, and the

value placed on exploration as a whole, (the exception on this last point was [E]), suggests wider agreement.

Exploring issues underlying symptoms rather than the symptoms themselves

(A,B,C,D,F,G,H) all seemed to find that exploring descending layers of experience underlying symptoms to be helpful, because it enabled them to develop an understanding of the meaning of this experience. (B) thought that by going deeper into these issues he has been able to gain a fuller understanding of the cause of his breakdown (B:140:1). For (G), accessing these issues started with exploring her feelings about herself (G:108:04), which led to examining the difficult relationship she had with her parents at times. In turn, this allowed her to start working through painful experiences of abuse (G:95:6).

5) Exploring the relationship between trauma, meaning and symptoms

Developing meaning seemed to be a major factor in recovery for all participants. For (A,B,C,D,F,G,H), exploring the meaning of experiences in psychotherapy seemed to be one of its most valued aspects:

(F:158:3) Every mentalist I know is incredibly traumatised...and completely fucked up. And you need therapy, you need someone to talk to.

Recovery began for (G) when she met an inspiring psychiatrist who ‘didn't see recovery just as possible, but inevitable’ (G:77:3). This led her to HVN and to exploring the meaning of her symptoms. Psychotherapy was the ‘second stage’ of her recovery, which was ‘less dramatic’ than the first, but ‘more meaningful’ (G:83:1-2). (F) thought the work he was doing with his PC Therapist helped him understand the

meaning of his voices, which he was no longer actively trying to ‘shut up’ (F:124:3).

(C) summed up why this process seemed important:

(C:154:2) I don't want it to be split forever. I figure these are my memories and these are my experiences, and I just wanna get to the point where I feel safe enough to bring them back into me, rather than have them as separate.

As with previous themes, the sub-themes help round out what was helpful.

Realising that thoughts and voices were not madness, but had meaning

Most participants seemed to find it helpful when psychotherapy facilitated an acceptance of the content of thoughts and voices. For example, in being told by his therapist that his thoughts were ‘normal considering my situation and the things that I'd been through’ (D:135:6), (D) realised:

(D:135:7) basically I'm not a raving lunatic after all, and I can have control over myself.

(G) had been terrorised by a voice that also appeared as a vision, which became less frightening, and then disappeared, when she began to understand its meaning.³⁴

Similarly, (F) found that in listening to his voices, he was able to ‘reconceptualise’ them as aspects of himself that had been formed by traumatic experiences (F:89:1-6).

(C) spoke in detail about how therapy helped her understand the meaning of her symptoms, which she thought had a protective function:

³⁴ This transformation can be seen in full in the next thematic grouping.

(C:34:15) [As a child, what] I was escaping from was the people who were hurting me, and so instead of having people who were hurting me as being people, they became monsters or aliens or *things*, separate.

However, this separation also happened *within* her. For example, when looking in the mirror, the ‘badness’ that had been put in her by the abuse made her see:

(C:41:3) this horrible monster looking back at me and I looked round and my friends didn’t react funnily. And I think I kind of figured that... underneath it all I was a monster.

Psychotherapy helped (C) to understand that the voices and visions that represented these feelings and experiences were protective:

(C:29:4) I didn’t want it to be real, and I have a very metaphorical kind of brain, so some people might be, “*As if* this is happening”, for me “This *is* happening”, and it gave me a lot of comfort actually.

Like (C,G), (A,B,D,H) all found that in understanding how symptoms contained a similar meaning and function, they became less frightening. However, all bar (H) spoke about how much fear they still evoked, as we can see in the next sub-theme.

Understanding the relationship between trauma, meaning and symptoms was painful, but it was helpful to persevere

Most participants felt that listening to symptoms, such as voices, and what they represented was painful, but necessary:

(C:28:1) Therapy for me is like having your insides ripped out and it hurts so much, it hurts more than I've ever, ever thought anything could hurt, looking at your stuff as having meaning hurts...

(C) felt at times it was less painful for her to slip into psychosis as a form of self-protection. In this state she believed she was a machine:

(C:28:7) Which basically meant that I didn't have a history and that I was basically made and all of this stuff that I was remembering, all the bits my voices were remembering weren't real and I was just given those memories ...

Despite feeling she was finally in a safe enough place in her life to address the issues underlying her symptoms (G) found psychotherapy initially made her feel worse because it was the first time she had acknowledged how hurt she had been by past experiences (G:91:1). During the early years of counselling (A) was not able to speak about being bullied because it triggered persecutory voices:

(A:120:1) I was out on the street and they would start picking on things that happened to me or [I had] talked about. And 'cos I had a thing of telepathy, I would think the busy street could hear it, all my internal - I was naked to the world...

Despite a commitment to explore the content of his voices with his Lacanian psychoanalyst (A) did not yet feel ready (A:79:10). (C) also found psychotherapy triggered her voices. For example, the Not Yet voices (as in the voices she was not yet ready to address) would make threatening comments about her and her therapist (C:18:8), while one of her internal personalities, Alfie, would try and make (C) stab

herself (C:27:1). (D) meanwhile found describing some of the experiences that he had made sense of during therapy was painful in itself:

(D:23:3) They're very painful memories... Even though it's good for me to talk about them, it's not something that I relish.

Most participants spoke about how painful experiences continue to haunt them, which made some cautious about how they proceed in psychotherapy. For example, (B) thought one to one therapy might require him to go too deeply into his experiences (B:139:6). (E) meanwhile, seemed similarly wary, because to 'deal with my shit' (E:54:1) would risk a complete 'meltdown' (E:45:5). However, (H) found that 'one very important thing that's come out of therapy' is that she can now 'really feel pain and then it's ok' (H:57:11)

In being able to persevere through this pain, (A,B,C,D,F,G,H) all spoke about developing a greater understanding of their experiences, which seemed to bring about a more effective reduction of symptoms than the attempt to control them. We can see this in more detail over the following two themes.

6) Facilitating a greater understanding of self

This understanding seemed to be an important aspect of recovery. For example, (H) thought family therapy started a process of 'introspection' that was 'like a self-recovery' (H:49:4-8). (A,B,C,D,F,G,H) all spoke about how developing an understanding of their inner processes worked and what experiences these related to helped them to function in the world. (C) summed up the value of this powerfully:

(C:31:2) It's kind of like the Matrix. Once you take the pill, you can't un-see... this different world.... (C:38:1) I don't think I'll ever go crazy again. Not properly. I think I might go through periods of psychosis to get away from all this, but I don't think I could ever spend eight months in hospital and believe I was schizophrenic.

Four sub-themes describe different aspects of the overall theme.

Understanding issues within family helped participants to understand their own experiences

(A,B,D,F,G,H) spoke about how understanding their families helped them to make sense of their own experiences. In particular, understanding some of their parents' own difficulties was useful:

(F:46:3) One of the things that therapy was very helpful for me was trying to understand her (*mother*). (F:46:6) she had a very difficult life. (F:48:5) I think she was deeply unhappy.

(B) thought that while his parents had good feelings about him, they had nothing to say to each other (B:34:2-8), and his relationship with his father had been 'terrible' (B:30:4). (H) believed her mother's strict Catholic upbringing (H:22:13) had played into 'the intense pressure we were under... We just lived in fear of my mother' (H:21:1). (A) experienced a similar pressure in the form of what appeared to be unconditional love from his mother. However, he felt in reality it came with a proviso that he had to be a version of himself that she approved of *before* he could receive it. This led to a deep confusion:

(A:165:9) When I started having difficulties, I wasn't a good boy. So she could manipulate me by telling me that I was making her upset because I wasn't the good boy that she gave unconditional love to...

In turn, he felt this confusion lay at the root of his questioning of his own reality (A:168:1-A:171:4). (D) described a similar confusion in how his mother's treatment of him made him feel everything about himself was bad, and this led to him thinking all his thoughts were madness (D:95:1). However, in exploring how his mother had seemed traumatised herself and how her bottled up feelings were expressed in a voice she heard, (D) felt psychotherapy helped him to understand that he had responded to his own difficulties in a similar way (D:116:4-8). By exploring these issues, (D) felt he began to establish an identity for himself that was separate from his family's problems, and this helped him to feel more stable (D:82:6-22). (H) found that by talking over and over her childhood experiences of loss of power, she healed her relationship with her parents, and was then able to have different kinds of relationships with people (H:57:1).

Understanding fears about sexual identity, or sexual relationships

(B,D,F) spoke about how psychotherapy helped them to understand that anxiety about sexual identity had been a key driver in their breakdowns. This understanding helped (D) to piece together the thoughts and actions that led to his breakdown, and the murder he committed after it:

(D:134:2) I thought he was Ronnie Kray, who was a well-known homosexual man. (D:133:1) I didn't want to turn gay. And that's why I killed my victim. I suppose I was very confused at the time. I didn't know who I was, so I was confused about a lot of things, especially about my sexuality...

(F) heard the voices of childhood bullies, God and the Devil, who all persecuted him for being gay (F:134:1-6), which he had always denied. However, when he finally acknowledged his deeply repressed bisexuality, he found a greater degree of self-acceptance and a reduction in the anxiety that was associated with the voices (F:63:1).

(B) discovered a similar sense of relief in in group therapy, where he was able to speak about the gay rumour at school that had traumatised him (B:116:11), to the point where it 'has actually come out of my system now' (B:117:7).

(A) found similar anxieties centred on his sexual relationships with women, which he thought mirrored issues of trust in his parents' relationship (A:170:1-1:171:4). These were anxieties that he thought to be a key factor in his initial breakdown (A:24:1-A:37:3).

Understanding how experiences expressed themselves as symptoms

Previous sub-themes have touched on how psychotherapy helped (A,B,C,D,F,G,H) to understand how symptoms expressed life experiences. We will look at this now in more detail. For example, (A) thought his persecuting 'Fact Voice' represented his experience of being bullied at school (A:87:3). (A)'s voices would often attack his thoughts, so he would try to avoid thinking at all 'just in case I got attacked' (A:107:1). This reminded him of Jeremy Bentham's Panopticon, which was designed in such a way that prisoners would never be free of surveillance (A:104:1). When (A) explored this further, he realised that the panicked and fearful state induced by this endless surveillance (A:108:1) seemed expressive of his boarding school experience, where toilets and dormitories were open plan, for this exact purpose (A:108:3-A:111:5). This led (A) to wonder during psychotherapy:

(A:112:1) “Is there a possibility I’m escaping the strict authoritarian regime of the school in my breakdown”.

(F) recognised an array of voices that he had begun to define as internal personalities, all of whom related to aspects of his experience (F:5:4-F:13:3, F:106:1-F:125:7). (G) discerned a similar relationship (G:48:1-G:58:12), as did (C), who found that naming her voices helped her to develop a relationship with them, and understand more deeply the aspects of herself they represented and the experiences to which these aspects related (C:35:2-C:45:11). (H) thought the pressure she experienced from her mother (H:21:5) was expressed as feelings of despair, paranoia, and self-loathing (H:9:7-H:12:12). (B) found a similar pressure of expectation from work and family and fears about his sexuality led to an ‘escape’ into schizophrenia (B:142:8-B:143:4). (C,D,G) all thought psychosis had this sort of protective function, and this theme is explored in more detail in the next thematic grouping.

7) Addressing meaning reduced symptoms

(A,B,C,D,F,G,H) spoke about how addressing the meaning of symptoms in psychotherapy led to a reduction in anxiety, which seemed then to reduce the voracity and severity of symptoms, such as paranoia and hearing voices. A number of sub-themes help us explore this from different angles.

Therapy helped to examine reality, reducing confusion and paranoid

(B) found group therapy helpful in distinguishing paranoia from what was ‘real’ (B:119:3), and this seemed to reduce feelings of paranoia. In realising he was traumatised, but not mad, (D) felt more in control of himself, which in the context of what he spoke about implied feeling less paranoid (D:160:1), and this helped him go

from ‘strength to strength’ (D:82:20). (A) thought his ‘superego’ made him doubt his own reality (A:80:3), and working with the meaning of this in psychotherapy helped him to build up his confidence (A:80:5). Although not explicitly mentioned, in the overall context of what he spoke about, building this confidence seemed to reduce feelings of anxiety.

Therapy helped to experience painful emotions, which made them less painful

In this sub-theme (C,G,H) all spoke about how making contact with painful emotions, such as anxiety, helped to make these feelings less painful. For example, (H) used to feel that strong emotion would damage her, and so needed to bury it, but gradually learned to experience and value it in therapy (H:57:11-17). Similarly, (G) realised that she used to hide negative emotions ‘by developing this very strong pleaser part, which I needed to survive my dad in a way’ (G:104:2). It was helpful when her therapist drew attention to how she deployed this pleaser part, by saying “You don't have to keep me happy” (G:106:1). (C) recognised that while therapy was painful, engaging with this pain was an essential part of understanding the meaning of symptoms (C:28:1-10), and addressing this pain made the trauma itself less painful (C:71:9).

Understanding feelings of self-loathing reduced anxiety

Feelings of self-loathing were present for many participants and working through this seemed to have far-reaching effects. (G) was able to develop a more accepting, loving relationship with herself, which meant she didn’t need to constantly adapt to what she *thought* others wanted from her (G:101:1). This was significant because her fear of displeasing others was a cause of anxiety (G:104:1). (F) meanwhile always felt he was ‘completely unattractive and weak and pathetic’ (F:88:1), and doing anything wrong,

such as making a cup of coffee in ‘the wrong way’, would lead to him telling himself “You're pathetic and stupid” (F:88:10). He felt, however, that he ‘stopped having bad thoughts through the therapy and through working on myself’ (F:89:7).

Understanding voices lessened anxiety, which reduced frequency of voices

Previous themes described how helping participants to understand the relationship between traumatic life experiences and the meaning of symptoms in psychotherapy led to a reduction of anxiety. In this sub-theme, we can see how this seemed to then had a direct impact on voices. For example, (D) found voices became ‘more distant’ like an occasional ‘whisper’, because:

(D:180:1) When I first heard the voices, I was petrified of them. But like now I'm not frightened of them, so they - I don't know if I can see them coming back.

(B) also spoke about how the fear arising from insecurities about his sexuality (B:117:5) dissipated by addressing this in group therapy (B:117:7). Since then:

(B:126:2) the angry, cruel voice left me and this friendly voice started returning.

In general, (B) found that he experiences voices now more like thoughts (B:122:5-B:124:1). Similarly, (F) found that by listening to voices and understanding their meaning, he hears them ‘[a] lot less’ now (F:93:1), and those he does hear include voices that are kinder and more supportive (F:9:3-F:13:3). (G) also found that once she understood that her most persecuting voice represented the part of herself that ‘had been harmed the most’, she recognised ‘he needed the most care and compassion’ (G:48:8-9). Proving this care and compassion to that part of herself led

to the voice disappearing altogether as a vision, and what was heard faded considerably and became kinder and more compassionate (G:60:4-11). (C) found developing a similar relationship with the most hurt aspects of herself brought about a change in her voices. Although (C) did not talk directly about lower anxiety leading to less frequent or attacking voices, she did speak about the reverse. For example, when her psychiatrist became anxious over (C)'s wish to come off medication, (C) became anxious herself, and her voices started 'yelling' at her in response (C:67:1-3). (A) suggested a similar link when he talked about how increased levels of anxiety and stress were often related to the presence of voices in the past (A:41:1-A:48:1).

6.3.5. TGv) Recovery

This thematic grouping focuses on recovery as a whole. While psychotherapy seemed an integral part of recovery for (A,B,C,D,F,G,H), other important factors were involvement in peer support networks like HVN, community support bodies, supportive relationships, self-sufficiency and work:

(G:3:8) [T]he recovery response is accepting, and integrating and understanding the emotional meaning of your experiences...

(A) summed up a second important aspect of recovery:

(A:179:1) Recovery is not about cure, it's about living, you know, finding a way of life.

1) Understanding the meaning of symptoms is central to recovery

The role of meaning in psychotherapy recurred in various thematic permutations in the last grouping. This first theme focuses on the role that meaning played in recovery

as a whole. Extracts from (C) and (G)'s exemplary portraits are used to illustrate this theme, as well as extracts from several individual depictions:

(C:71:15) Network for Change... and the Hearing Voices Group... were... the first people that really said, "There's a meaning here, there's something, this isn't just an illness randomly grabbing you and dragging you like a demon into hospital where other people make you better".

As with previous themes, a number of sub-themes help us appreciate different aspects of this theme.

Listening to the content of symptoms is more helpful than trying to block them out

In previous groupings we saw how (A,B,C,D,E,F,G,H) all found the attempt to suppress symptoms medically was less helpful than listening to what symptoms were saying. (G) encapsulated the overall group experience:

(G:51:1) [I]t was [seen as] this arbitrary symptom of mental illness... a piece of biological bad luck to be endured, rather than a complex, or significant, or meaningful experience to be explored.

In exploring these meanings in both psychotherapy and through her involvement in HVN, (G) found her voices became less attacking, and more supportive (G:3:13-15). Similarly, (D) found that by listening to his voices he realised they represented two girls that he had once had a complex relationship with (D:64:3-D:68:9). This understanding seemed to reduce his fear of them, and they faded to a memory (D:180:1). (F) found the medical attempt to block out his voices rendered them a background white noise, but in listening to them he understood they were 'memories

coming back that I had suppressed for years' (F:5:2). As we saw above, (C) had a similar experience. (H) meanwhile believed that recovery started as soon as she ended medical treatment:

(H:38:2) [O]nce I was free of the shackles of the medication I was able to start thinking for myself, making decisions for myself...

The short period of family therapy that came soon after this was 'part of the recovery process' (H:45:3); subsequently study and work were helpful (H:39:2-3). However, listening to her experiences in more detail did not come until some years later when she began long-term psychotherapy. (B) found medication useful, but was frustrated that it was all that medical treatment had to offer. When he listened to his symptoms rather than trying to suppress them, he began to understand the experiences that had contributed to his situation (B:141:1). By listening to his symptoms (A) found that his experiences were a 'perfectly understandable... reaction to what I was going through' (A:147:10), and that medication blocked his capacity to understand his feelings (A:141:22).

While (E) found therapy helped her talk about some of her experiences, HVN peer support groups were felt to be 'more therapeutic and more helpful' (E:68:3). In the process, she began to understand how experiences such as being sexually groomed as a child, and then being raped as an adolescent, expressed themselves in one of the persecuting voices she heard (E:24:2-10). However, she also seemed wary of what would come from this understanding (E:54:1).

Voices represented traumatic experiences, such as bullying and sexual abuse

In the previous grouping we saw how voices or visions were sometimes expressive of an actual experience (A,D,E,F), a metaphorical representation of this experience (A,B,C,D,E,F,G,H), or an aspect of self that associated itself with the experience (A,B,C,D,F,G,H). (C,E,F,G) all began to make this link after coming into contact with individuals or peer support networks that encouraged them to look at the meaning of their experiences. Because (E) was the only participant who didn't seem to find psychotherapy helpful in this area, and because we have seen others' experiences in the previous grouping, this sub-theme is illustrated by (E)'s experience alone.

After unhappy experiences at primary and secondary schools (E) began to make friends at university. However, following the breakup of a relationship the voice of her abuser appeared and threatened to jeopardise her new friendships. This mirrored the threat made by her actual abuser:

(E:24:6) [H]e was just like, "I can take all this away from you. I'm going to tell [your parents]... They're going to know everything... You're sick".

Listening to the content of voices brought about an understanding of the experiences and aspects of self they represent, a decrease in anxiety, and a reduction in voices themselves

In the previous thematic grouping we saw a relationship between understanding the meaning of experiences, a reduction in anxiety, and then a reduction in voices themselves. (C,F,G) illustrated this relationship vividly in the way that they linked voices and visions with aspects of themselves that were associated with traumatic experiences. (C,F) both found naming these aspects helpful. For example, (C) named

the monster voice/vision Alfie, who is ‘basically me as a child’ (C:40:11), and who carries that experience ‘as a voice or as an aspect of me’ (C:40:12). One benefit of having a relationship with these aspects is they hold memories that (C) is not always conscious of herself (C:70:13-18). Similarly, (F) had named his fourteen year old bullied self ‘Jonathan’, who expressed his ‘rational side’ (F:104:1); ‘Panic’ expressed his anger (F:9:1); ‘Kay’, an eleven-year-old ‘gay prophet’ expressed his creative side (F:7:4); and ‘Viva’ represented a comforting, maternal character (F:9:3).

(G) provided a striking example of how understanding the meaning of symptoms brought about their reduction, which is worth representing in some detail. (G) thought that the first voice she heard expressed her disowned anger, and her right to be heard and to matter (G:30:4). The medical attempt to suppress this voice led to a ‘psychic civil war’ in which the initial voice multiplied into twelve (G:44:5-G:46:5). (G) believed this process transformed her from the ‘unhappy teenager’ into a ‘schizophrenic’ (G:42).

These new voices were dominated by one particularly fearsome voice, which also appeared as a shadowy, tall man, swathed in black, and who had a butcher’s hook instead of a right hand. This figure would ‘slither around the ward’ and hissed like Milton’s depiction of Satan (G:47:4-11). Because this apparition provoked terror, (G) would:

(G:48:10) work to the point of exhaustion to try and blot him out and not acknowledge him.

However, (G) found that by listening to the voice she began to understand it as:

(G:48:5) a hugely amplified version of that original voice that reflected my own emotion.

(G:48:7) [H]e represented the aspects of me that identified with the people who'd harmed me.

So the part of me that felt, "You deserved it, you asked for it, you're bad, you're dirty, you're flawed, you're destined to suffer, your whole life is going to be cursed."

In recognising this, she began to understand that:

(G:48:12) he needed the most care and compassion.

In responding to the voice with compassion, rather than terror and avoidance, (G) found it became increasingly benevolent, and its visual manifestation disappeared altogether (G:60:7):

(G:60:10) It's almost like he became more integrated into me... (G:61:1) [H]e was the voice that definitely caused me by far the most problems. But he was also the voice that held the real key to the healing in him as well...

Psychosis is a survival mechanism that protects the mind from traumatic experiences

In the previous thematic grouping we saw this sub-theme in various guises. (B,C,D,G) all thought psychotic symptoms were a way of protecting themselves from trauma that was too painful to experience directly, through the distance of metaphor. For example, (G) felt that dissociating from traumatic experiences was a protective way of removing them from memory (G:16:6-12). (D) thought that his personality was 'retarded' by the mentally confined space he was born into, and 'schizophrenia' was a way of escaping this impossible situation (D:16:2), without which, he would have killed himself (D:16:7). Similarly, (B) felt that his breakdown was an escape from the pressure to maintain a version of himself that didn't feel true (B:142:8-B:143:3). (C)

found that visions of monsters were less painful than actual abusers (C:34:15-17). However, while less painful than the memory of abuse itself, psychosis was not a 'fun' refuge (C:33:1). Crucially, (C) believed that in being able to address the meaning of these painful experiences there was no longer a need for the protection of psychosis (C:31:2-C:38:3).

There is a spiritual or advanced technological dimension to hearing voices

(B,E) both believed that their psychotic experiences were related to past trauma. However, both also thought voices might arise from an ineffable dimension. For example, while (B) seemed to feel that the interrogating voice of the devil represented his fears about his sexuality (B:117:1-B:119:2), he also thought the voice might also be the actual devil himself (B:120:5). Similarly, while (E) thought some voices represented past trauma (E:24:6), others might represent a supernatural dimension or a form of advanced technology that she didn't yet understand (E:85:1-E:86:1). (E) also thought an interpretation of her experiences which involved her having 'some kind of special powers' was 'more positive' than interpreting them as 'mental illness' (E:82:1). Echoing this sentiment, (F) thought in another culture he would be regarded a shaman or prophet, rather than 'a schizophrenic' (F:161:4).

Having addressed underlying issues voices can often be helpful now

(C,F,G) all spoke about how in finding a relationship with their voices they now expressed good feelings as well as bad, rather like thoughts themselves. For example, (F)'s Viva voice was felt to be healing and comforting (F:9:3). In understanding the meaning of his symptoms (B) seemed to suggest that the persecuting voice suddenly

left and a friendly voice returned (B:126:2). As a result, voices appeared more like thoughts now (B:122:5-B:124:1).

(C,G) both spoke about how their voices often express an emotional reaction to an external event that had not consciously registered (C:153:1-12), (G:129:2). This allowed them to address the external event and to calm the voice itself, because they understood *why* the voice was anxious (C:149:4-C:149:10), (G:131:1-G:133:12):

(G:2:5) what's changed is the way that I relate to them because I understand so much better,
and I feel like there's a relationship between me and my voices that's quite good and
constructive...

2) Coming off medication helps further recovery

All participants, apart from (B), felt that coming off medication either had, or would help further their recovery. (A) considered medication a form of management rather than an aid to recovery. Some felt that medication suppressed emotions that needed to be felt in the process of psychotherapy (A,C). While coming off medication triggered symptoms to return (C,D), which was frightening, these could be worked through and so diminished (C,G). An important benefit of reducing or coming off medication was the concurrent reduction, or loss, of side effects, such as lethargy and confusion. (C,F,G,H) all thought these side effects hampered the ability to function in work.

(C,G,H) no longer take medication. (A) was in the final stages of coming off it, while (E,F) were reducing their medication with a view to being medication-free. (D) wanted reduce his medication, but was wary of doing so.

3) You need to work against the mental health system to recover

Overall (A,C,D,E,F,G,H) found the mental health system an obstacle to recovery. (C,F,G) thought the attempt to suppress symptoms was counter-productive. (C,D) believed the mental health system was a dumping ground, and (C,G,H) had to actively work against the treatment provided by it to recover. (G) thought that in promising a fix, but being unable to deliver, the mental health system failed patients, and was like an abusive parent. Most participants felt that there were problems in the way professionals regarded patients. Being conceptualised as a biologically flawed person reinforced deep feelings of being useless (C,F), or a problem (A). (C,E) thought that a person's life experience should be more important than their diagnosis. Taking charge of one's own recovery was seen as important (C,G,H), and some felt that a greater degree of peer support in the mental health system would be helpful (A,C).

4) Other recovery factors

(A,G,H) found supportive personal relationships crucial. For (D,F) long-term relationships with support workers was helpful. Other useful factors were being involved in work (A,C,D,E,F,G,H), exploring their life story while taking part in a film about their experiences (F), being treated by a nutritionist (H), exercising (E), exploring sexuality (B), and developing philosophical interests (A).

5) Entering mental health field as a professional and using experience to help others

(C,D,E,H) found working with others who were in a position that they had once occupied enabled them to use their experiences as a force for good, and helped them to continue exploring the meaning of their experiences. For example, (C) valued her

work as a mental health service project manager, and (E), her work as a psychiatric nurse. (D,H) were training to become a counsellor and a psychotherapist respectively.

6.4. Creative synthesis

The experience of both schizophrenia and psychotherapy seemed deeply woven into a ‘focal’ (Mousatakas 1990:24) picture of the participants’ embodied life experiences. The process of completing the composite depiction raised the question: ‘How might my understanding of the experiences researched be synthesised into a creative representation of this “focal” embodied experience?’ It occurred to me that embodied experience was in some ways analogous with a physical environment that is shaped by multiple interacting agents, such as the weather, minerals, fauna and flora, which form a constantly evolving landscape that is both seen and unseen. With this concept in mind, the embodied experience depicted here appeared as a multi-dimensional entity, in which the realms of experience, meaning and intersubjectivity dialectically meshed together as a ‘mind environment’.

Just as the ‘subsidiary’ (Moustakas 1990:24) aspects of a physical environment may be viewed through any number of lenses: aesthetic, geographical, cartographical, meteorological, zoological, etc., this mind environment can be viewed through the lenses of psychology, neuroscience, psychiatry, sociology, and so on. In *both* kinds of environment, however, any single lens incompletely describes the whole. The metaphorical narrative that follows attempts to represent the mind environment picture suggested by the participant’s experiences, as I understood it.

Childhood

The environment comes into being. Rocks with a mineral inheritance form a three-dimensional relief into which life will erode and lay down its deposits of experience. Early on, something is not quite right. Powerful, but often unspoken, elements flood the environment from the outside: contempt (F), overbearing control (H), abuse (D). Communication becomes difficult (B), and so the environment withdraws inwards (G).

Trauma

One day a meteor blazes out of the sky and tears into the environment, uprooting trees, gouging boulders from the soil. The meteor is many-sided: a paedophile in your nursery (G), the vicar who rapes you (C), a violent father who leaves you at the mercy of your troubled mother (D), the school bullies who single you out (F). The environment doesn't have the experience to make sense of what's happened. It has learned not to speak about what it fears, so nobody notices. A silent holocaust.

Fear swells the floodwaters, until the ground gives way under the pressure and the water drains away underground. The environment is scarred, but it has survived. There is a cost to this new equilibrium, however.

Confusion

Underground, the floodwaters open up caverns with their acidic action of self-loathing (F), shame (G) and depression (E). Now when it rains, the water follows this established path. Extreme measures are required to prevent collapse: "I'll split myself into nice and bad" (G), "I'll become popular to mask what's going on inside" (B),

“Taking drugs will help me forget” (A), “Cutting myself will make me feel better” (E), “If I’m violent, others won’t see my fear” (D). In disowning the caverns, their gnawing pain now belongs to someone, or *something*, else: a bisexual gangster (D), a monster (C), the devil (F).

Second trauma

Trees have taken root and grass covers the scarred earth. The environment looks like any other, but deep underground the ‘squishy black mess’ (C) continues to erode. The terror of collapse is fended off with rituals: multiples of 13 to be avoided (H), collecting rubbish (G), searching your flat for bugging devices (D). A feather landing could bring it all down. In the event, it’s much bigger: a relationship breakdown (A), a university tormentor (G), being raped again (C,E), the gay rumour that burrows into you (B).

Breakdown

As the environment collapses in on itself the surface is plunged into the dread-filled caverns. Voices come out of the darkness. Some speak the words of tormentors (A,D,E,F). Others retch up their emotional content, but are thrown out of shape like reflections in fairground mirrors (B,F,G). More rituals are needed to avoid them: “Lose them in the street” (E), “Don’t think and they won’t attack you” (A). But they don’t go away. Desperate measures are needed now: “Jump off a bridge” (F), “Drill holes in your head” (G), “Kill your tormentor” (D).

Finally, the outside world notices. The collapsed environment can no longer function. Other environments look on mystified. “Where on earth does all this come from?”

Treatment

Geologists, meteorologists, zoologists all offer their professional opinions. But it's the geologist whose opinion counts. He's seen this kind of thing before many times (A,C,G). It's called schizophrenia, a severe and disabling rock disease. This analysis is reassuring at first (A,C,H), because it helps all involved not to think about the black chaos beneath (A).

The geologist begins the treatment. Thick concrete is poured through the collapsed surface into the caverns beneath. Some voices become muffled, some disappear altogether, but others get louder, angrier (G). Worse, the surface is sealed into the cavern now. New problems emerge: dizziness and epilepsy (F), eyes rolling back into the head (A), semen drying up (D). Sometimes these add to the terror: "Aliens are making me lactate!" (C). Different kinds of concrete are added to deal with the side effects, and then more concrete to deal with *their* side effects.

Time passes. Geologists come and go with new concrete prescriptions. Warning tape encircles the environmental disaster within. Occasionally, meteorologists are admitted beyond the tape by the geologists, but often with the purpose of helping the environment to develop 'greater insight' into why the concrete is necessary.

Initial recovery

It starts with a spark of defiance (H); perhaps an encouraging word from a geologist with vision (G), a meteorologist who listens (C), or meeting recovered environments (A,E). They all suggest there might be meaning in the voices. Sometimes this idea is

too frightening – more comfortable to think of yourself as a disaster area (C).

Sometimes it offers immediate hope (G).

Psychotherapy

At times, the work is unhelpful. Some meteorologists only know about water, so they try to help the environment to deal with the symptoms of flooding alone: “Ignore the voices, they’re not real” (A). Others are professional, but they don’t seem interested (B,F). Others again don’t seem to know what they’re doing, and stick too rigidly to guidebooks and maps (C). They’re well meaning, but can’t be trusted.

At other times, the work is helpful. Just feeling listened to is reassuring (C). Feeling liked (B), being told your thoughts are normal (D), or building a trusting relationship (F) all help. The black waters of dread recede just enough for a question to form:

“What’s in here beneath the concrete?” Some meteorologists are uncomfortable with the question: they’ve never entered a cavern before. Others are prepared to descend into the shadows to be with the collapsed part of the environment. They listen to the voices together and explore their source. However, picking out the shards of meteor is painful (C), and this work initially makes others think it would be better to stop (G).

By seeing further into the surrounding darkness the environment finds the knowledge to rebuild itself. New structures rise up and support the collapsed surface, and water drains away. Finally, in the sludge left behind, the environment faces the most feared voice (C,F,G). It can shift shape and commands huge power (B,E,G). But now the environment realises the voice is its own terror. Care for this most damaged part grows (G). In return, the voice is comforted and no longer needs to invoke terror to

make itself heard. So it leaves in the night (B), fades to an occasional whisper (D), argues only when you're arguing (A), becomes a calmer, more helpful companion (C,F,G), or never returns (H).

On-going recovery

Now when it rains, the water passes through more freely. The concrete plug inhibits the on-going growth of the underground supports. Some remove the concrete altogether (C,G,H), others reduce it (A,F,E). Some feel more comfortable with the support it offers (B,D).

Facing voices still brings fear (A,C,E), but in understanding its own experience better, the environment can see how it relates to surrounding environments. It can see where the water originates, and what to do when it pours. Being aware of more than just isolated, abstracted parts, the environment can see itself now as a picture, a habitat, an eco-sphere, a story, or a person. They are an environment in flux: a living, breathing Being. Not just a set of faulty rocks.

Chapter 7

A crisis of meaning

7.1. Introduction

It will be helpful to briefly review the process that has led to this final chapter. The study began with an autobiographical connection to what was researched. Immersion in first person experiences of ‘schizophrenia’ while making a documentary film (Cotton 2010) and reading first person accounts of the phenomenon (some of which are detailed in Chapter 3) then helped to shape the research question: ‘What are the psychotherapeutic experiences of those with a “schizophrenia” diagnosis’? The search for a suitable methodology to empirically investigate this question was described in Chapter 4. The method used to carry out the research was then detailed in Chapter 5, and the procedures of data analysis and the resultant findings were presented in Chapter 6.

To summarise these findings, the answer to the research question seems as follows: ‘The psychotherapeutic experiences of the participants have been characterised by a struggle with meaning. Psychotherapy, and treatment as a whole, seemed helpful when this struggle was facilitated, and unhelpful when it was obstructed’. This empirical discovery might appear obvious for two reasons. Firstly, phenomenology, the principle discourse which this study is situated within, tends to regard meaning as central. Secondly, movements such as HVN conceptualise recovery as ‘reclaiming meaning’ from the medical complex. Because the majority of participants were involved in such discourses it follows that psychotherapy would be considered helpful if it furthered meaning-making. So embedded was the importance of meaning that I had failed to grasp its *significance*. However, what emerged in the process of this study was a deeper understanding of this significance. This understanding led to a deeper appreciation of Heidegger’s interlocking concepts of understanding, possibility, meaning and care,

which in turn, culminated in the (inevitably inadequate) terms, ‘personal’ and ‘medical’ meaning, which are explored along with Heidegger’s concepts in Chapter 3.

(Re)viewed through this lens, interviews yielded a rich volume of personal meaning about the phenomenon researched, and these empirical findings are discussed in three sub-sections in the first part of this chapter (7.2.). In the first sub-section (7.2.1.), what was found to be helpful about treatment is discussed, and this is followed by what was found to be unhelpful (7.2.2.). Both sub-sections can be summarised as follows:

‘Meaning seemed to play a central role in both ‘schizophrenic’ breakdown and recovery for participants. Crucially, *how* meaning was *treated* in treatment as a whole either seemed to facilitate recovery, or prolong breakdown’. This meaning dynamic is then explored in depth in 7.2.3., and leads to the argument that the recovery of a (personally) meaningful self might be facilitated by an ‘anticipating care’ (Boss 1963:73), while the ‘intervening care’ (*ibid.*) that is prevalent in medical meaning treatment might produce long-term ‘broken selves’ (Bollas 2013), in whom meaningful selfhood has been ‘colonised’ (McCarthy-Jones 2012:316). This discussion is contextualised with the findings from Chapter 6, the issues examined in Chapters 3 and 4, and the most relevant literature reviewed in Chapter 2. Consistent with the aims of this study, technical psychotherapeutic language has been avoided in favour of descriptive terms. It is hoped that my understanding of the participants’ meanings does justice to them. However, it is acknowledged that in basing the argument that develops in this chapter on these meanings they may have been ‘colonised’ by my own.

The second part of this chapter explores the implications of this study for clinical practice, as well as wider social implications (7.3.). After this, the implications of the

study for my own practice and myself as a ‘learner and a person’ (Moustakas 1990:54) are reflected on (7.4). This is followed by a critical review of the study (7.5.), and then recommendations for further research (7.6.). The chapter concludes (7.7.) with the ‘essence’ of the study, and its significance for both myself and for others (*ibid.*).

7.2. Discussion of findings

Exploring the meaningfulness of ‘symptoms’ seemed an important driver of recovery for all participants. With the exception of (E), all participants found psychotherapy helpful when it supported this meaning-making process. This overall finding seems consistent with the three most relevant texts reviewed in Chapter 2 (Dillon 2012, Lauveng 2012, O’Brien 1960) as well as D’Ombraine Hewitt (2012), Leszcz *et al* (1985) and Mohelsky (1994). Moreover, it was through this meaning-making lens that participants reflected on the life experiences that had contributed to their breakdowns, their experiences of treatment overall, and their recovery process. The structure and chronology of these events, in particular the role of traumatic life experiences, also closely resembles the experiences detailed in Cotton (2010), Dillon (2012) Lauveng (2012), and the majority of the *50 Stories of Recovery* published in Romme *et al* (2009); and a similar structure was also suggested by O’Brien (1960). Conversely, treatment, particularly when governed by medical meaning, which attempted to suppress or control ‘symptoms’, seemed to disable this meaning-making process and so prolong, or intensify breakdown. This finding seems consistent with Cotton (2010), Dillon (2012), Lauveng (2012), O’Brien (1960) and Romme *et al* (2009). We will look at these findings more closely now in three sub-sections.

7.2.1. What was helpful

The thematic pattern that emerged most strongly from **TGiii) Psychotherapy that was helpful** was the quality of the relationship (safety, trust, feeling on an equal footing with the therapist, the therapist's awareness, and the capacity for openness about what was happening in the relationship), and the freedom and space to explore the meaningfulness of experiences within this relationship. Reflecting this pattern, Lauveng (2012) found there was three essential qualities of 'time, safety and space' (p131) within the psychotherapy relationship. Being listened to intently (*ibid.*), and 'stuck with' patiently (p129), even when for years little progress was made, provided a crucial framework within which she could 'explore the connections between my symptoms and my life' (p56). This emphasis on relationship and a reflective, non-directive, exploring approach bore a close resemblance to the 'therapeutic alliance' that Dillon (2012) found was 'the key' to transforming her 'subjective reality of a terrifying internal and external world' (p19). The importance of the therapeutic relationship has been highlighted by several researchers. For example, after reviewing a large number of psychotherapy outcome studies, Wampold (2001) found that the therapy relationship itself was responsible for 'psychotherapeutic benefits rather than the ingredients specific to the particular theories' (p23). Gelso & Carter (1994) also found this relationship to have a pivotal role, yet note that it is the most under-researched aspect of treatment. Thomas & Bracken (2005) seem to endorse these findings from a psychiatric perspective, in noting that despite all the 'assumptions, priorities, meanings and values' employed in 'psychiatric technologies... a great deal of their success is determined by the relationships in which they play a role' (p168).

To understand what was helpful about the combination of the quality of relationship and the space to explore meaning we need to first return to the ontological examination of the relationship between trauma, meaning and ‘psychosis’ that was begun in Chapter 3. Contextualising this relationship with the findings will help us to see how personal meaning seemed to play a key role in breakdown and recovery for participants, which in turn reveals why this thematic pattern might have been helpful. This examination roughly follows the chronological thematic ‘storyline’ (McLeod 2001:145) used in each of the procedures shown in the last chapter. This helps us to retain the ‘focal’ aspect (Moustakas 1990:24) of this ‘storyline’ structure, while examining its ‘subsidiary’ aspects (*ibid.*) through a progression of lenses.

In researching experiences of psychosis, Geekie (2012) found that:

[P]articipants emphasized the importance of telling their *own* story, which made *personal* sense to them, rather than simply accepting a “ready-made” explanation of what their experience should mean to them (p89).

This led Geekie (2012) to conclude that ‘finding this meaning in life’ was one of several ‘crucial components’ of recovery (p88). Lauveng (2012) meanwhile seemed to credit the development of this self-authored meaning (which we could equate here with personal meaning) with coming to ‘understand the world and my role in it (p155)’. The notion that both a person’s ‘story’ and their ‘role in the world’ might be central to recovery seems to support Heidegger’s argument that one’s *own* ‘authentic’ (Gelven 1989:70) meaning lies at the heart of being a ‘meaningful self’ (p75). Crucially, for both the participants here and for Dillon (2012), Lauveng (2012) and O’Brien (1960) the experience of trauma seemed to shatter the complex relationship between the meaning-

making individual and the external meaningful world, in the manner that Bracken (2002) suggests (p2).

Participants seemed to initially manage the experience of trauma by splitting themselves into separate compartments. For example, (G) ‘split’ herself between an “academic self” and a “secret self” that was filled with ‘fear and shame and horror’ (G:6:3-8). By early adolescence, the widening gap between split parts seemed to make functioning in the world increasingly difficult. For example, (H) thought that her inability to enter into adult life in this state led to her breaking down (H:37:13). This process of splitting and breaking down seems similar to O’Brien’s (1960) recollection that by her ‘early teens’ she had become ‘a departmentalized child’ (p146). Managing this compartmentalisation required killing off the parts that did not fit, with the consequence that wholeness was lost in order to gain acceptance of a single part (p152). While achieving a defensive short-term aim, in the longer term, this kind of fragile self-structuring seemed to lead to the terror of collapse for many participants. A second phase of trauma that was experienced by all participants in adolescence or early adulthood then seemed to bring this feared collapse about.

With the internal world ‘broken’ and in a ‘state of upheaval’ (Bracken 2002:59) ‘the meaningfulness of the world’ may then require being ‘withdrawn’ because it is too painful (p1). Schore (2012) seems to support this notion from a neurological perspective in observing that one response to trauma is to protectively ‘dissociate’, which involves the withdrawal of a meaningful, present self (p81). Beck & van der Kolk (1987) found a complimentary form of self-protection in trauma being transferred to a metaphorical realm. For example, in their study, ‘[h]igh rates of

sexual delusions’ were found in psychotic incest survivors’ (Read *et al* 2004:235). As we saw in the last chapter, this kind of metaphorical expression of trauma was a recurring theme. Why should this be important?

(C) believed she had unconsciously transferred memories of sexual abuse into a metaphorical ‘as if’ realm (C:29:5), where the trauma was expressed by the voices and visions of monsters and aliens. This attenuated ‘psychotic’ remove was felt to be marginally less painful because it enabled her to lose ‘the meaning’ of her ‘overwhelming’ original trauma (C:32:1). This protective metaphorical expression of trauma was also illustrated by (B,D,G), and like (C), (B,D) also found that ‘schizophrenia’ offered an escape from an intolerable psychological situation. O’Brien (1960) found a similar protective refuge in ‘[i]nsanity’, which ‘was for me, a training programme, accompanied by escape from actual stress until I could gain what I needed psychologically to face the same stress in actuality’ (p150). Similarly, Lauveng (2012) remembers a protective withdrawal into ‘psychosis’ when faced with ‘even the smallest uncertainty’ (p79). However, in such a broken state Cromby & Harper (2009) suggest that ‘paranoia’ may feed back into the underlying anxiety, and so intensify it (p355). The impact of anxiety related to suppressed traumatic experience, or what DSM refers to as aetiologically distinct ‘mood disorders’ (APA 2005:345-48), on ‘schizophrenic symptoms’ was also noted by (A,B,C,D,E,F). In the wider literature, both Boll (1999) and Chadwick (2009) make this link as well. Lauveng (2012) also notes that in this state the line between metaphor and ‘literal things’ became increasingly blurred for her (p11), heightening her confusion. In essence then, ‘psychosis’ may offer the mind protection from trauma until it can be

faced. However, this ‘psychotic’ state seems acutely sensitive to the underlying anxiety that is being avoided.

Bollas (2013) supports this notion from a psychoanalytic perspective, arguing that far from being the onset of a debilitating ‘disease’, in ‘breakdown’ the psyche may be attempting to throw up its contents into consciousness to be worked with, and meaning to be addressed (p18). In doing so, ‘impending catastrophe’ can be transformed ‘into a potential space for profound change’ (p98). This notion of breakdown seems similar to Heidegger’s argument that it is in the breakdown of the enslaving ‘actual’ that one finds the possibility of a meaning that is authentically one’s *own*. The ‘actual’ in this instance might be both the mental structures developed by a person in order to protectively ‘dissociate’, the resultant ‘symptoms’ that assail them, or the cultural and medical meanings used to then interpret these defences as signs of a meaningless ‘disease’. To transpose this notion back into Gelven’s (1989) car analogy (pp95-96), in the mind breaking down we have the possibility of understanding more about its constituent parts and how they might work together in a way that helps us to function more authentically, and therefore *freely*.

Participants seemed to illustrate how this notion of breakdown and ‘profound change’ led to recovery for them. For example, (C) found the gradual process of bringing painful experiences back into her conscious mind, as opposed to her mind protectively ‘dissociating’ from them (C:154:3), allowed for the meaningfulness of ‘symptoms’ to be addressed. In turn, this seemed to lead to an irreversible recovery of a personally meaningful self, which no longer required the protection of ‘psychosis’ (C:31:2-5). (F) found that by ‘conceptualising’ his voices as a ‘dissociation’ from traumatic

childhood experiences (F:89:4), he was able to discern them as separate characters that reflected buried aspects of himself, and (A,B,D,E,G,H) all spoke about similar experiences. During his psychoanalysis, Mohelsky (1994) found similar detailed meanings in the ‘mosaics in a landscape’ - the metaphors of experience expressed in his psychotic ‘symptoms’ (p35) – which led to his recovery.

(G) described this kind of transformation in detail (G:47:2-G:61:3), and noted how the most persecutory ‘symptoms’ seemed to represent the most damaged aspect of herself, which ‘needed the most care’ (G:48:8). When attended to, these ‘symptoms’ faded, or disappeared altogether (G:60:4-11). Lauveng (2012) describes an uncannily similar process of transformation. For example, in her psychotherapy, when she began to explore the meaning of the harrowing wolves that had stalked her for years from one hospitalisation to another, she began to understand them as ‘just emotions – recognizable human feelings’ (p36) that had taken on ‘psychotic’ dimensions when suppressed. In so doing, ‘images and emotions began to have words and stopped being unmanageable images only’ (p155). The most traumatic ‘symptoms’ were then revealed to her as ‘only a marker – a beacon’ whose ‘light went out all on its own’ (p28) when their meaning was attended to. (A,B,C,D,F,G,H) all described a similar process, in which ‘symptoms’ became less frequent and voracious, or disappeared completely, when their meaning was addressed in this manner.

These experiences suggest that in participants recovering personal meaning, a process began in which traumatic experiences were slowly moved from a ‘psychotic’ dimension into a ‘non-psychotic’ dimension. In this sense, the ‘profound change’ that Bollas (2013) refers to might be considered a re-integration of a shattered mind, in

which selfhood can once again ‘face the dread brought on by a struggle with meaning’ (Bracken 2002:2). Facilitating this process for another - whether one calls it helping them to recover personal meaning, to self-author, to understand themselves, to ‘decolonise’ themselves from an alien Other meaning, or to free them from an enslaving ‘actual’ - seemed to be an important way of aiding their recovery.

This facilitation seemed remarkably similar to Heidegger’s mode of anticipating care that was detailed in Chapter 3, which gives ‘back to him authentically as such for the first time’, because ‘it helps the Other to become transparent to himself *in* his care and to become *free for* it’ (pp158-159). It is this mode of care, that Boss (1963) describes as an ‘existential unfolding’ (p73) when applied to psychotherapy, which seems to closely correspond to the thematic pattern that characterised what was found helpful. We should note, however, that participants seemed to experience the benefit of this anticipating care not just in helpful psychotherapy, but also in support structures ranging from family and friendships, to social worker relationships and peer support networks, such as HVN, which we saw in **TGv) Recovery**. Very broadly, we can also see the conditions that supported this kind of care in the four areas of **TGii) Inpatient and residential treatment** that were found helpful. These were good relationships with psychiatrists, feeling safe in hospital and camaraderie with other patients, diagnosis taking experience into account, and medication where it helped take the edge off ‘symptoms’ and aided function in everyday life.

7.2.2. What was unhelpful

What was unhelpful seemed the inverse of what was considered helpful. To examine this more closely we will start first with **TGiii) Psychotherapy that was unhelpful**,

before coming to the aspects of **TGii) Inpatient and residential treatment** that were considered unhelpful.

The thematic pattern that emerged the most clearly from **TGiii) Psychotherapy that was unhelpful** was a nexus between the psychotherapy relationship not feeling good and the obstruction of a free exploration of experiences. For example, at the most fundamental level, when participants felt they had no choice in who they worked with (A,C,E), felt disliked (B) or not respected by their therapist (F), or thought they were dismissive (A), too blunt (H), or domineering (C) it was not surprising that it did not seem safe to explore the meaning of, what were often, painful experiences. Moreover, the feelings attached to these same experiences were often unwittingly ignited. For example, the feeling of being ‘turned into a thing by people’ (F:154:2), believing oneself to be “the problem” (A), or feeling powerless and abused (C,F). These kinds of ‘transferences’ were useful when openly explored (A,C,G,H) because they led to an understanding of the experiences that prefigured them. However, when not acknowledged or noticed (either because they were not deemed relevant to the psychotherapy aims, or because of the therapist lacking awareness), they seemed to replicate and *reinforce* past trauma.

While the personal bearing of therapists seemed to play into this nexus, the rigidity of theory also seemed to play an important part. This study was not structured in a way where empirical comparisons between modalities would be useful: there were not enough participants, and modality comparison was not an aim. However, there were two theory models that stood out in this regard. The first was CBT which was thought to have rigid notions of what was ‘normal’ and ‘pathological’ thought, which closed

down the possibility of exploring the meaning of experiences (A,C), or required experiences to be edited to fit into its framework, and felt like a ‘conveyor belt’ (C:88:5). Although less forthright about what she thought was unhelpful about associated clinical psychology, (E) seemed to feel ‘paralysed’ by not being able to work in the way she thought her therapist wanted (E:53:2). The second was psychoanalytic psychotherapies, which to a lesser extent, seemed unhelpful when theory seemed applied rigidly, rather than being rigid *per se*. For example, (C) found techniques like ‘repetition’ distancing (C:137:6), while the perceived ‘demand’ to form a secure attachment to her therapist seemed dominating (C:151:2), and being deemed to have poor ‘ego integration’ (C:108:3) was felt as a rejection. Similarly, the ‘blank screen’ approach seemed to alienate (F), but his distress (if noticed) did not seem to prompt a change of tack, implying a similar rigidity in the way the theory was used.

In essence then, while there was less detail available in **TGiii) Psychotherapy that was unhelpful** than its counterpart, we can see the outline of a pattern in which the exploration of personal meaning seemed to be closed down, either by the personal bearing of the psychotherapist, the theory framework used, or the *way* this framework was used. Significantly, this pattern closely resembled what seemed unhelpful in **TGii) Inpatient and residential treatment**, which could be summarised as follows. Psychiatric diagnosis was often felt to be arbitrary (C,E,F,G), to ignore the context of experience (C,E,G), and did not address the meaning underlying ‘symptoms’ (A,B,C,E,F,G,H). Treatment based on medical meaning assumptions then focussed on the attempt to suppress ‘symptoms’ with medication, which further distanced their underlying personal meaning (A,C,F,G,H). Hospital was felt to be rigid, controlling

(C,D,G,H) and re-traumatising (C,G), and seemed to lead (A,C,F,H) in a direction that was similar to (G)'s transformation from 'unhappy teenager' to 'schizophrenic'.

There was little reference to unhelpful qualities of psychotherapy in the literature reviewed in Chapter 2. However, the three most relevant texts (Dillon 2012, Lauveng 2012, O'Brien 1960) all described similar unhelpful qualities in their psychiatric treatment. Lauveng (2012) brings into sharp focus how the domination of personal meaning by medical meaning might impact on recovery.

[T]he important questions in life are: Who am I? Where do I want to go?... And which dreams do I have for my life? And an ICD-10 diagnosis can never answer these questions. Therefore, the Captain didn't really care much about the diagnosis. He continued to shout until I got help seeing what he represented (p28).

This raises the question of whether CBT/clinical psychology and psychoanalytic psychotherapies were the most prominent modalities in **TGiii**) because of the frequency with which they were encountered, or because of their proximity to medical meaning. For example, Rapley *et al* (2011) argue that mainstream psychology's support of 'the positivist psychiatric project of codifying human suffering into disease-like categories' is problematic (p1). Similarly, Parker *et al* (1995) note that psychoanalysis 'often functions as a compliment to the mainstream medical model' (p23). Both, at times, may also mirror 'modern descriptive psychiatry's' tendency to ignore 'important data' (Roe & Lysaker 2012) and its 'naïve realist stance' (Cromby & Harper 2009) toward experiences whose meaning cannot easily be explained within its objective framework. We should note, however, that conceptual rigidity was not the preserve of medical meaning treatment. For example, (C)

found the supposedly reflective TC treatment model to be inflexible because reflection was seen as an *a priori* mode of that model, with the result that there was little facility to genuinely reflect on *not* reflecting (C:102:4). We should also note that (C) also found the ‘tips and techniques’ that she learned during her CBT were helpful (C:95:2), and (E) thought the ‘perspectives’ of her clinical psychologist were also helpful. Similarly, psychoanalytic psychotherapies were found helpful by (A,C,G,H), particularly when they facilitated the exploration of meaning.

These exceptions aside, we can summarise that by far the most prominent thread running through treatment *as a whole* that was thought to be unhelpful was the way in which medical meaning was used to *explain* participants’ experiences with ‘pre-existing categories of thought’ (Laing 1965:33). This explanation seemed to close down the possibility of exploring the personal meaning underlying ‘symptoms’, and seemed to be intrinsically bound up in an intervening care that ‘leaps in and dominates’ (Heidegger 2008:159) meaningful selfhood. The relationship between medical meaning and this mode of care is explored in the next section, and it is speculated why the combination of the two may be not just unhelpful, but actively harmful.

7.2.3. Medical meaning and intervening care – a crisis of meaning compounded?

Bracken (2002) notes that in psychiatric and psychological treatment there is an assumption that ‘the meaningfulness of our lives’ can be analysed like ‘biological systems’ (p10), and so the *breakdown* of meaning is assumed to *arise* in these systems. In Chapter 3, we saw how the medical meaning assumptions, in which the ‘symptoms’ which are deemed to arise in these same systems/substances are ‘not dependent on context’, and are treatable by ‘technological interventions’ which can be

‘designed and studied interdependently of relationships and values’ (Bracken *et al* 2012:430), are problematic.

Moreover, we saw how a growing body of research (Read & Bentall 2012) suggests that rather than arising in ‘biological systems’, or ‘substances’, life experience might play an important role in shaping them. In the previous two sub-sections, we also saw how these critical arguments seem to be supported by the findings here. In this section, we will look more closely at the impact of these medical meaning assumptions on treatment, and in particular, how the ‘technicalization of the problem of meaning’, which starts with the ‘need to act, to intervene... might actually be making the situation worse’ (Bracken 2002:8-9). To examine *how* the nexus between medical meaning and intervening care might be making the situation worse, we will begin with a closer look at the disjuncture between medical and personal meanings in light of both the findings and the experiences detailed in Chapter 2.

In Chapter 3 it was noted that the DSM conception of ‘schizophrenia’ centres on ‘Criteria A’ ‘positive symptoms’, which are characterised by ‘delusions or prominent hallucinations’ (APA 2005:299), whose ‘pathological nature’ the patient is deemed to lack ‘insight’ into (p297). There are three principal problems with this conception, which we will be examined now, followed by a brief examination of the remaining aspects of ‘Criteria A’ and ‘Criteria B’.

The first problem is the assumption that voices and visions are inherently ‘pathological’. Both phenomena are noted to be experienced by the ‘normal’ population (Boyle 2002, McCarthy-Jones 2012), and as the findings here suggest, it is the *content* of these

experiences rather than voices and visions *per se* that seem to be distressing. For example, in addressing the content of her most feared voice (G) found it became kinder to her and faded (G:48:1-G:61:3). This notion seems consistent with Longden *et al*'s (2012) suggestion that it would be more helpful to conceptualise voices on a 'continuum' with thought, and as with thought, the attempt to suppress voices may 'paradoxically heighten the likelihood of occurrence' (p52).

The second problem is the objective excision of existential content and context from 'observed behaviour', dimensions that have been noted here to be central to personal meaning. As we saw above, both the findings and the literature reviewed in Chapter 2 repeatedly illustrate how 'symptoms' tend to be a meaningful expression of life experience once content and context are taken into account. The 'naïve realistic stance' toward 'psychotic' experiences (Cromby & Harper 2009:338) in which this content is disregarded seems untenable in this light. To encourage a person to regard such experiences as *meaningless* may well have the consequence that all personal meaning becomes mistrusted.

The third problem is the reliance on the clinician's supposed objective judgement of whether the patient's experiences involve 'misinterpreted' or 'erroneous' beliefs. Rather than being objective, such judgements are inevitably coloured by the embedded Western cultural assumption that 'psychosis' is 'the irrational writ large' (Ellwood 1995:1). This assumption seems reinforced by, for example, the diagnostic term 'Praecox-Gefühl' (or 'praecox feeling'), which refers to the 'examiner' being 'unable to establish any empathetic understanding with the ['schizophrenic'] patient' (Alanen 2009:4-5). In this sense, the examiner's culturally informed lack of understanding confirms their subjective

interpretation that the patient's 'symptoms' signify a 'disease' process, and their personal meaning is therefore *de facto* 'erroneous'.

Crucially, all three problems feed into a fourth, in which the experiencing person may be further alienated from the position of author of their own meaning-making. For example, 'authentically' occupying this position seemed central for recovery, and being forced from this position seemed to have radical consequences for (A,C,D,F,G,H), as well as Dillon (2009, 2012). This notion of authenticity is a crucial point in the argument being developed here, and we will return to this shortly.

While 'delusions' are described in DSM-IVTR as occupying the 'Psychotic Dimension' (APA 2005:299), a second, discrete 'Disorganised Dimension' (*ibid.*) is thought to be characterised by 'Thought Disorder' and 'Disorganised Behaviour' (p300). Moskowitz (2005) argues that rather than viewing the former as a stand alone 'symptom' it makes more sense to view it as spoken snippets of a more expansive, partially spoken thought narrative. This wider narrative might then blend traumatic 'associations from past events with the current context' and leave the listener, who is only party to the current context, confused (p4). (F) seemed to illustrate this conception in believing he must be travelling through time when he first began hearing the voices of his past tormentors (F:5:3), and Dillon (2012), Lauveng (2012) and O'Brien (1960) all detailed similar experiences. Participants also amply illustrated that the reasons for 'disorganised behaviour' became clear once the 'survival strategy' context that they existed within was understood. For example, (H)'s counting rituals, (G)'s preoccupation with trepanning and (D)'s search for bugging devices.

We also saw in chapter 3 how ‘Criteria A’ ‘Negative symptoms’ were conceived as a lack of fluency of thought and speech, and difficulty in carrying out goal-directed tasks (APA 2005:301). However, as participants made clear, struggling with persecuting voices and visions can be frightening and demoralising, especially when they are construed as the meaningless ‘symptoms’ of a ‘disease’ that is considered ‘worse than cancer’ (G:32:15). At the most fundamental level, this is likely to kill off hope, a key component in recovery for Lauveng (2012:160), as well as for most participants. Such despair seemed compounded by being unable to work because of medication side-effects (A,B,C,D,F,G,H), or experiencing stigmatisation and the decline of ‘normal’ social interactions, three areas that Lauveng (2012) identifies as obstacles to her recovery. DSM-IVTR itself recognises that such ‘co-morbid symptoms’ may be either naturally occurring, or associated with other factors such as ‘medication side effects, depression, environmental understimulation, or demoralisation’ (APA 2005:301). However, making the distinction between these kinds of connected factors and unconnected ‘symptoms’ once again relies on subjective ‘clinical judgement’ (*ibid.*).

The final aspect of determining the diagnosis relies on a critical sum of criteria. In addition to ‘Criterion A’, one or more aspects of ‘Criterion B’ must be observed, which include social or occupational ‘dysfunction’, and a duration of ‘symptoms’ over 6 months (APA 2005:312). However, these criteria seem to describe experiences similar to ‘Negative symptoms’, and are likewise understandable once one takes their existential context into account.

In summary then, if one’s *understanding* of ‘schizophrenic’ experience incorporates personal meaning, one may see a range of connected, meaningful ‘symptoms’ that

express underlying issues which require attention. By contrast, when these same ‘behaviours’ are *explained* with medical meaning what one sees are discrete medical ‘symptoms’, the *meaningless* ‘signs’ of a ‘disease’, which require suppression with medical interventions. Because the latter approach dominates research and treatment, those with the diagnosis must overturn their own *valid* personal meaning in order to acquiesce to a subjective meaning structure that is itself rife with ‘misinterpreted’ and ‘erroneous’ beliefs. We will now look more closely at the consequence of this domination, and the intervening care that enables it.

In Chapter 3, it was noted that the objective knowledge situation that underpins medical meaning requires both the professional and the patient to be rendered neutral, ontologically *unmeaning* ‘person-Things’ (Heidegger 2008:155). Binswanger, Boss’ contemporary, outlines how the attempt to produce such an objective ‘perfect tense of theoretical investigation’ in the psychotherapy relationship involves replacing a ‘reciprocal, “personal” communication within a we-relationship’ with a ‘one-sided, i.e. irreversible, relationship between doctor and patient’ (Binswanger *in* Friedman 1991:414). ‘Like medical treatment’, this intervening care approach ‘makes a deliberate project out of changing the patient in certain specific ways, in conformity with a preconceived concept of health’ (Burston 2000:53). In this sense, we can rest on the notion that intervening care and medical meaning treatment are inexorably entwined.

However, Geekie (2012) found the imposition of mental health professionals’ ““ready-made”” explanations of what patients’ experiences should mean to them unhelpful because they overrode ‘their *own* story, which made *personal* sense to them’ (p89).

Lauveng (2012) examines this issue from the perspective of the ownership of meaning.

[T]he symptom is owned by the person who has it, and only that person alone holds the answer to what that exact behaviour means in that exact situation (p33).

From a Heideggerian perspective, we might refer to this as an issue of ‘authentic’ Being, which, as we saw above, involves occupying the position of architect of one’s own meaning-making. In order to embrace the professional’s ‘ready-made’ medical meaning of the ‘symptom’, (and to display ‘good insight’ into one’s ‘illness’), the patient must override ‘that which he is to concern himself’ (i.e. personal meaning), and in so doing ‘is thrown out of his place’ (Heidegger 2008:158). ‘Authentic’ Being (and the capacity for self-authorship) is therefore replaced by an ‘inauthentic... “non-self-mode”’ (Gelven 1989:73-74), whose focus is not on ‘*my own* Being’ but ‘the Being of “they”’ (p121). Lost in this ‘They-self’ Being ‘loses sight of the self’ and covers it up (p71). Care that intervenes in this way inevitably leaves a person ‘dominated and dependent, even if this domination is a tacit one and remains hidden from him’ (Heidegger 2008:158).

Might the consequence of having one’s meaning-making capacity dominated by an alien ‘non-self’ be that *all* experience is then mistrusted, and so the anxieties about what is ‘real’ and what is not are intensified, rather than alleviated? When we look more closely at this meaning and care dynamic, we can see how states of ‘dissociation’, ‘depersonalisation’ (perceiving oneself to not be a person) and ‘derealisation’ (perceiving oneself as not ‘real’) - the ‘associated features’ of

‘schizophrenic symptoms’ noted by DSM-IVTR (APA 2005:304) – might actually be compounded.

For example, (F) believed he had no alternative but to accept that his voices were a meaningless ‘white noise’ that needed to be blocked out. In being encouraged to ignore the content of this white noise, to accept one’s ‘disease’ and passively wait for the right balance of medication to ‘manage’ it (G), and to feel that one has no option but to also accept side effects that make social function and work difficult (A,D,F,G,H), Being seems defined by being ‘schizophrenic’. (C) seemed to find this position meaningless beyond conforming to a set of diagnostic characteristics (C:161:5). Lauveng (2012) likens these characteristics to one of her schoolbooks, which stated: “‘the horse is an ungulate that stems from the ancient horse *eohippus* with three toes’”. Whether being categorised as an ‘ungulate’ or a ‘schizophrenic’ such statements are ‘completely useless’ (p106) because they say little about ‘the very unique circumstances that made them what they are in a specific situation’ (p107). Being ‘schizophrenic’, therefore, may place one in a kind of double negation. From a medical meaning perspective, ‘symptoms’ are meaningless, and in having to accept this explanation one also has to accept becoming an objectified ‘person-Thing’, which is in itself ‘unmeaning’ (Heidegger 2008:193). In both cases, the important question: “How must I think about what it means?” (Gelven 1989:83) does not seem possible. Dissociating from such a torturous position might seem the only alternative.

This kind of dissociation seemed compounded for participants by feelings of ‘depersonalisation’ and ‘derealisation’ in two linked areas. Firstly, (C,E,G) recalled having to edit their experiences in order to fit arbitrary diagnostic categories. Having

experiences ‘carved at the joints’ (Rapley *et al* 2011) in this way seemed to result in the sensation of being split into pieces by the treatment (C:4:5). This splitting seemed to unwittingly mirror O’Brien’s (1960) coping strategy of becoming a ‘departmentalized’ person (p146), which required killing off the parts of herself that did not fit, and in which wholeness was lost in order to gain acceptance of a single part (p152). Secondly, as well as usurping the experiencing person’s meaningful selfhood, forceful medical intervention (C,E,F,G) also seemed to mirror past experiences of powerlessness (A,C,F,H) and abuse (C,F,G), which may have themselves required participants to become protectively ‘derealised’, ‘depersonalised’ and ‘dissociated’.

However, because ‘this domination is a tacit one and remains hidden’ (Heidegger 2008:158) such feelings may have no explicit root and so become further dissociated from their source. With such a link lost, ‘*our* inability or unwillingness to understand’ (Burston 2000:69) the person thus dominated becomes further ‘evidence’ of their ‘disease’, and this feeds back into the problem. In this sense, we can grasp why the meaning dynamic underlying intervening care might, to appropriate Laing (1967), simply perpetuate ‘the disease it purports to cure (p45). Both the effects of medication, and the *way* it was used, seemed to powerfully reinforce these dynamics. We will look at this now in more detail.

Consistent with Chadwick (2006, 2009), Stanton & David (2000), Coursey *et al* (1995), Wagner (1996), Anon1 (1989) and Anon2 (1990), medication was helpful for most participants in the early stages of treatment. However, unlike the above, most participants found that both its side effects *and* its potential benefits had serious

implications for recovery. Lauveng (2012) summarises this balance in acknowledging that medication may ‘ease the pain’, but can also trap people in ‘a diseased state and keep [them] from moving on with active therapeutic transformation’ (p137). Why might this be the case?

From a neuropsychanalytic perspective, Koehler (2012) notes that anxiety may be a major factor in driving ‘psychotic symptoms’. This view seems illustrated by most participants’ experiences, and notably, NICE (NCCMH 2010) also seems to acknowledge this link (p23). In focussing on suppressing ‘psychotic symptoms’ with medication, participants found that anxiety often remained unaltered and continued to drive these ‘symptoms’. As noted above, when the experiences relating to this anxiety (such as trauma) were addressed, most participants saw a decline in the voracity and frequency of ‘symptoms’, and where they remained, voices tended to become helpful and less critical. In essence then, in not addressing traumatic experiences or anxiety related to them, medication seemed to have little effect on what may be an important driver of ‘symptoms’.

Beyond compounding lethargy and social isolation medication also had complex psychological effects. For example, (C)’s fear of alien invasion was reinforced by the side effects of Risperidone (C:54:8), while the sensation of being chemically overpowered reminded (H) of being a powerless child (H:38:2). Medication also seemed a signifier of ‘compliance’, which also provoked anxiety. For example, (C)’s attempt to come off medication was met by anxiety from her psychiatrist, which then made her anxious. This anxiety then produced ‘psychotic symptoms’, which were interpreted as evidence of (C)’s ‘relapse’ (C:66:1-C:69:11). Moreover, side effects

such as weight gain, drooling and loss of sexual function, all seemed to reinforce the anxious, despairing self-image of Being ‘schizophrenic’. In this sense, medication *and* what it symbolises may have the capacity to exacerbate issues underlying ‘symptoms.’

Even when medication successfully suppressed ‘symptoms’ - for example, (E,F,H) felt it made little difference - the content of voices was blunted along with associated thoughts and emotions, and so those who wanted to work with their meaning found it more difficult to do so. Bolas (2013) notes that while it may initially be helpful ‘in the immediate situation... ingestion of such drugs negates meaning’ and obstructs the ‘[d]iscovery of the unconscious reason for the breakdown’ (p18). (G) seemed to confirm this view: ‘[I]f I wanted to negotiate this strange subconscious world in a constructive way, then I sort of needed my wits about me to do it’ (G:119:2). Taken together, these factors might go some way toward explaining why 40% of those with the diagnosis have ‘a poor response’ to medication (NCCMH 2010:27).

What then of the argument that coming off medication leads to worsening ‘symptoms’, as (D)’s experience, for example, seemed to suggest (D:173:1)? Harrow & Jobe’s (2013) twenty-year study of antipsychotic usage confirms this is a common experience in the first six to ten months of being medication-free. However, the research suggests that the increase in ‘symptoms’ at this point seems to correlate with the brain re-adjusting to its pre-medicated state, and those who remained medication-free went on to fare better than their medicated peers. Consistent with the experience of participants who had either come off medication all together (C,G,H), or who were reducing it (A,F), Karon (2003) found that psychotherapy without medication had the best outcomes for those

with the diagnosis, closely followed by psychotherapy with initial medication which was gradually withdrawn.

Treatment approaches to 'schizophrenia' that place a greater emphasis on exploring the meaning of 'symptoms', rather than the attempt to suppress them with medication, seem to support this finding. For example, in Finland's Open Dialogue approach, which places the meanings of those with the diagnosis at the centre of an on-going supportive dialogue with family, employers and mental health professionals, 67% of participants in a twenty-year study of the model were not given any form of antipsychotic medication at all during their treatment (Thomas, S. 2011). Yet only 33% experienced 'relapse' within five years (*ibid.*), a stark contrast to the 75% 'relapse' and 'continued disability' rate of those being treated (NCCMH 2010:18) in the UK's medical approach. Similar statistics are noted by Whitaker (2010): 73% of those treated with antipsychotic medication in America return to hospital within three years, as opposed to just 8% of those who were given a placebo (p101). Andrew *et al's* (2012) research into employment amongst those with the diagnosis seems to reflect this worrying correlation between long-term medication and long-term illness. In 1970, employment amongst those with the diagnosis was at a high of 60% (only 10% lower than the national average), but has plummeted to a contemporary low of 'between 5 and 15%' (p9). This timeframe seems to closely correspond with the unprecedented growth in the market for antipsychotic medications (Mosher *et al* 2004).

Bollas (2013) argues that medication tends to 'seal over the structuralized breakdown and unwittingly ensure its permanence' (Bollas 2013:18). Such a state seems to unwittingly mirror, as Heidegger sees it, the tranquillisation that the dominated

‘inauthentic’ self seeks in the ‘actual’. This tranquillisation is likened to an addiction in which ‘Dasein has become blind, and puts all possibilities’ into its service (pp239-240). This is undoubtedly a contentious argument, but might medication remain a central pillar of medical meaning treatment *despite* poor outcomes precisely because it fits with an intervening care ethos in which patients are dominated and managed?

Reviewing all of these arguments together, might medical meaning intervening care be more likely to produce a ‘symptom-managed’ ‘broken self’ (Bollas 2013), enslaved in the ‘actual’ and ‘addicted’ to a painful self-alienation, rather than aiding a recovery of selfhood in which a person is ‘transparent to himself *in* his care’ and ‘*free for* it’ (Heidegger 2008:158-159)? Put in medical meaning terminology, might the combination of medical meaning and intervening care facilitate the passage from ‘prodromal schizophrenia’ (APA 2005:302) to ‘acute schizophrenia’ (p307), rather than promoting recovery? This argument seems born out by the majority of participants who found mental health services that were characterised by medical meaning intervening care an obstacle to recovery, rather than an aid. This argument also seems supported by, amongst others, Whittaker (2010) and Breggin (2008), who both argue that the medical emphasis in mainstream mental health care in America often leads to long-term disability, rather than recovery. In this complex meaning and care dynamic, then, one starts to appreciate why the ‘colonisation’ of meaning experienced during treatment that is embedded in the ‘medical story’ (McCarthy-Jones 2012:316) might be experienced as an existential threat, rather than care.

7.3. Implications for clinical practice

We have seen how medical meaning intervening care might potentially obstruct recovery. Bracken (2002) cautions where psychotherapy is driven by this kind of urge to ‘order and control’ ever more efficient therapies ‘can be expected to generate new forms of oppression and suffering’ (p202). Yet it is just such an approach to care that NICE (NCCMH 2010) seems to embrace. For example, might ‘adherence therapy’, which aims to enhance ‘compliance’ with medication (p28), be considered a form of psychotherapy, or a form of control? While less overt, might the NICE conception of CBT, which is characterised as offering ‘interventions’ in which patients ‘re-evaluate their perceptions, beliefs or reasoning in relation to the target symptoms’ (p258), be a more subtle form of control? For Ross & Read (2004), the coercive impulses of both seem ‘unprofessional and unethical’ (p110). If this is the case, might the efficacy of treatment measured by RCT be better described as the efficacy of control? Rather than providing an alternative, therapies such as art therapy and family therapy are expected to adopt the objective values (p251 and p290 respectively) to which CBT and RCTs seem so well suited to, in order to be recommended. Should we be concerned that ‘the measuring tool now determines the therapy’ (Loewenthal 2008:149)? Ironically, the objective research that NICE draws on seems at odds with the qualitative research also drawn on. For example, while NICE recommends that CBT should be offered ‘to all people with schizophrenia’ (p274), of the three personal accounts featured, only ‘C’ had experienced CBT, and seemed to find it unhelpful (p56). Conversely, NICE recommends that counselling should not be ‘routinely offered’ (p290), yet it was the only psychotherapy modality that seemed helpful (‘Personal Account B’, p54).

As an ex-manager of a mental health service, I appreciate it is naïve to think a system that ‘measures capacity and patient output’ (Lauveng 2012:130) has room for the ‘years, and many therapy sessions’ that Lauveng required ‘to get well, because change and insight is a process that has to grow from within and can’t be hurried’ (p131). Yet, persisting with an approach to care that attempts to manage and control, but which may unwittingly worsen outcomes, seems a false economy at the very least. Rapley *et al* (2011) note that ‘[d]emedicalizing... human suffering’ is a ‘massive and multifaceted task’ (p5). Where to start? In sympathy with Heidegger, Laing and Polanyi, ‘understanding how we come to stand where we are’ in our use of theory (Parker 1999:4) rather than unquestioningly filtering all we see through it seems vital. This might then open up ‘psychiatrized and psychologized’ theory (Rapley *et al* 2011:5) to ‘what emerges in practice’ (Loewenthal 2011:4). In so doing, we might appreciate how caught up we are in the theories we use to ‘uncaringly’ (in Heidegger’s sense) explain a person before we are able to understand their personal meaning. Post-existential thought (Loewenthal 2008, 2008a, 2011), which draws on both Heidegger and Laing and, might offer one way of keeping this possibility open, and resisting becoming ‘embedded’ in the totalising theories that tend to be sought out in treatment systems. In opening up this kind of reflective, critical space to what is found in practice, the personal meaning of those being researched and treated could be considered not just valid, but *crucial* ‘data’. In this configuration psychotherapies that might facilitate personal meaning with anticipating care could find their place, rather than being squeezed out by the anxiety to ‘order and control’.

What might anticipating care look like in practice? In transposing Heidegger’s models of care into psychotherapy Boss’ (1963) Daseinsanalysis might seem an obvious model.

However, as Cooper (2003) notes, while the approach ‘advocates openness and flexibility it has its own tendencies towards dogmatism and closedness’ (p49). Besides, Boss himself noted that his conception of anticipating care was more of an ethos than a structure. Frankl’s Logotherapy (2011), with its emphasis on the search for meaning (Adler 1997), might be another possible approach. However, it seems Frankl believed that in the case of ‘schizophrenia’, a patient should be taught to ignore their voices (Boeree 2006), which, for reasons that we have seen, would be unhelpful.

Rather than getting caught up in literalism, one could perhaps focus on *how* personal meaning might be recovered. Burston (2000) notes that Laing believed most ‘schizoid’ patients struggled to differentiate between states of true and false guilt (p51)³⁵, and in so doing these states became merged into a monological attacking and belittling inner voice that left it difficult to “hear” other “inner voices”. Laing urged that *hearing* such voices might allow the patient to ‘understand’ the contents and function of false (or inauthentic) self construction, and so to heal the internal splits and ‘emotional deadness’ that are required to maintain it. This process might then aid the development of a truer self that is more capable of Being in the world (p40) authentically. This conception seems similar to the ‘Voice Dialoguing’ approach to working therapeutically with voices that was pioneered by Dillon & May (2002) and Coleman (2000) – all voice hearers themselves – and which occupies a key position in HVN discourse. Broadly speaking, the common thread between these approaches involves finding a way of opening up dialogue between aspects of self - whether expressed as externally ‘heard’ voices or ‘inner’ voices, or thoughts – as a way of

³⁵ This refers to Winnicott’s (1965) conception of true and false selves, which are similar to Heidegger’s authentic and inauthentic states, but also different in a number of ways. However, there is not the space here to elaborate further.

helping to develop both internal relatedness, and what has been termed here, personal meaning.

These aims seem consistent with a number of discourses besides Laing and HVN. One example might be Metcalf's (2012) relational psychoanalysis approach, in which selfhood is not considered singular but multiple; like an archipelago of islands, elements of which might be concealed at times. Another might be CBTp, or CBT for psychosis (Dudley *et al* 2009). On the surface an antithetical discourse, CBTp emphasises the importance of the relationship and understanding the individual's meaning of their experiences. In essence then, psychotherapeutic care that anticipates personal meaning might be found across a number of diverse approaches. What follows is a distillation of the qualities of psychotherapy found helpful by participants, which might be considered useful in this kind of anticipating care approach³⁶.

1) It seems helpful when the therapist attempts to empathically understand the experience of the patient, and the meaningfulness of their world as *they* experience it. Meanwhile, it seems unhelpful to attempt to explain these experiences with pre-existing 'categories of thought' (Laing, 1965). In point 3) two such categories are considered.

2) The quality of the therapeutic relationship seems important, as noted by Gelso & Carter (1994), Thomas & Bracken (2005), and Wampold (2001). Specifically, having a compassionate, understanding attitude toward the patient may help them to develop a secure relationship (where previously there may have been insecure, or damaging ones). This secure, compassionate relationship may then help the patient develop a

³⁶ While this is not intended to be modality specific, these qualities inevitably reflect the 'categories of thought' this study is 'embedded' in.

sense of trust, in which difficult material can be explored and worked through. This finding seems concordant with the work of Rogers (2004), who argued that the therapeutic relationship could be a key agent of change . However, this attitude should not harbour idealistic assumptions that empathy alone heals all, for reasons discussed in the point that follows.

3) Because the therapeutic relationship is important, paying attention to *everything* that happens within it seems vital. This is because, regardless of how one conceptualises the relationship, a complex web of narratives seems to emanate from both patient *and* therapist. Developing a reflective, holistic picture of how these narratives might relate seems important. These narratives can then be thought about, rather than ignored and so free to play themselves out tacitly in ways that replicate prior damaging experiences.

Two areas seem of particular importance. The first is ‘embedded’ theory. For example, focus on the ‘symptom’ seems to inhibit the free-ranging exploration of other crucial narratives, such as feelings of anxiety, life history, etc. The second is the therapist’s belief that they can excise their own Being and be present instead as a ‘perfect tense’ ‘person-Thing’ technician. This may ‘switch off’ their ability to understand what happens *between* themselves and the patient, and how their own personal meaning plays into the situation. While this may seem to relate to therapeutic approaches situated in objective discourses, the assumption that empathy heals all, for example, may be a similar *a priori* that enables the therapist to remove themselves from the situation. As Smail (2005) notes, in the example of Rogerian counselling, the counsellor’s ‘warmth and empathy’ may well carry with it ‘an expectation – all too easily turning to an obligation – to *change*’ (p83). Psychoanalytically one might say that not all

‘transferences’ and ‘countertransferences’ are positive, and expecting them to be so closes down important expressions of what might be taking place.

4) In appreciating the above point, it would be helpful for the therapist to have been through their own psychotherapy process. Through this they might develop a greater awareness of their own tangle of narratives and the interpersonal bearing they might have. Additionally, in experiencing for themselves the difficult processes that the patient will be experiencing, the psychotherapist might also develop a more empathic disposition toward the patient. In so doing they might be more able to conceptualise the patient’s meaning-making journey, rather than conceptualising treatment in meaning-stripped ‘perfect tense’ terms, such as ‘symptom-managed wellness’.

5) Psychotherapeutic theory can aid thought about what the patient might be experiencing and the complex meaning dynamic that occurs in the psychotherapy encounter. However, it may also be used to shut down what is found in practice to disastrous effect. Therefore, rather than *starting* with theory, it may be more helpful when it is used as a conceptual bridge from one stage of a meaning’s evolution to another. This bridge may then be discarded when it no longer fits what is found in practice.

6) Time and space should be given to the relationship for the patient to develop personal meaning at their own pace, rather than the pace that a therapeutic model dictates. This is not necessarily antithetical to a cash-strapped, time-poor statutory mental health system. By way of example, in the Finnish Open-Dialogue Therapy model (Thomas S. 2011) treatment lasts between 6 months and several years. The area

of Western Lapland where the model exists previously used a medical model, and had one of the worst treatment outcomes in Finland (Aaltonen *et al* 2011).

7.4. Implications for researcher as a person and practitioner

This study has accompanied me through a career change from filmmaker and part-time psychotherapist to full-time psychotherapist, both in private practice and as manager of a mental health service. It has acted as a constant, questioning companion on this journey, compelling me to think more deeply about the tensions between theory, what is found in practice, and the *Realpolitik* of treatment. In turn, what has emerged from this self-dialogue (Moustakas 1990:16-20) has constantly fed back into this study and the conclusions drawn here. This has been a profound learning experience, which has brought me back time and again to examining *my own* personal meaning.

McLeod notes that ‘reflexive knowing’, a core aspect of heuristic methodology, is ‘usually uncomfortable for the reader’ (McLeod 2003:4). As one would expect from a method in which the ‘investigator must risk the opening of wounds’ and undergo ‘personal transformation’ (Moustakas 1990:14) this study has not always been a comfortable experience for me either. This process has taken me back to my own experiences of breakdown and hospitalisation. Exploring these in my own psychotherapy has led to thinking more deeply about the experiences that contributed to them, and the aspects of psychotherapy that helped me to recover. I have been struck by how much anger I still feel about some of my treatment experiences, and how prevalent this feeling seems amongst people who have been through the mental health system. Such anger is not straightforward, and the complex dynamics at work

have been touched on above. Suffice to say, in a personal approach to research, getting passionately ‘caught up’ might not end in the interview process (Weber *in* Moustakas 1990:48), but might extend into writing up the research as well. However, perhaps allowing myself to be caught up has contributed to what has been reflected on here, rather than foreclosing on it. Either way, it seems to have helped me to speak more openly about experiences which, while always held to be central to my personhood and practice, previously seemed best kept separate from my ‘professional role’. It may even have helped me to experience more closely my ‘own unconscious “psychotic domain”’ (Alanen 2009:6).

My practice as a psychotherapist, both working with those with the diagnosis, and those without, has benefitted enormously from this study. In attempting to understand some of the underpinnings of ‘schizophrenic symptoms’, I have come to realise how similar they are to many people’s experiences, my own included. Above all, they seem fundamental to all human existence: the desire for one’s life to have meaning, and the terror that might stem from losing it.

The process of this study has strengthened my commitment to reflective, critical practice, and my desire to engage more vigorously with the discourses that are critiqued here. Currently, this takes two forms. The first involves on-going psychotherapy writing and conference work, and the second involves exploring these ideas in a creative form that might engage a mainstream audience. Of the latter, what has been learned during the course of this study has fed into a parallel feature film project, which attempts to transpose some of the arguments explored here into a dramatic structure.

Most importantly, this study has drawn me more deeply into the ethical questions that are crucial to psychotherapeutic work, but which often become reduced to ticking a box marked ‘ethics’. Might such automated ‘concern’ ironically encourage a lack of thought about what it means to regard the face of the Other (Levinas 1994) on an equal footing? The attempt to approach research on an equal footing *and* think about it has almost certainly failed here. However, the act of trying has generated knowledge that was not anticipated when this study began.

7.5. Critical evaluation of study

The empirical aim of this study was to explore the psychotherapeutic experiences of those with a diagnosis of ‘schizophrenia’, while the epistemological aim was to deconstruct the knowledge on which the diagnosis is grounded. These aims are evaluated in the areas that follow.

Study genesis

The structure of the study evolved relatively slowly. However, the intense self-questioning experienced during this process helped shape a design that has yielded some vivid, detailed experiences. While Cotton (2010) was a separate (although connected) piece of research, what was learned during that process was useful to this study, particularly in thinking about the ethics of representation and how to understand another’s meaning.

Participants

Apart from (B,H), all participants had some involvement with HVN, which may have influenced the overall group meaning of ‘recovery’. While this did not constitute a

homogeneous vision of recovery, or how psychotherapy either helped or hindered it, it might have been useful to include more non-HVN associated participants. However, as noted in Chapter 5, recruiting such participants was difficult.

Focus

Empirically, interviews could have been more focussed on experiences of psychotherapy. However, there was a vast richness in participants' life stories which it seemed psychotherapy had helped access, and so it was difficult to separate the two in a way that did not replicate the same 'depersonalising', context-stripping process that has been critiqued here. Epistemologically, it has been perhaps overly ambitious to draw together Heidegger, Laing, Polanyi and critical clinical discourses in support of personal meaning, and to use them to critique medical meaning. The postmodern emphasis in this study on multiplicity of meaning over modernist normative meaning may also illustrate the criticism that the former can fall prey to 'conceptual flaccidity' and may be 'generously inconclusive' in its 'nature' (Smail 2005:12).

Overall, the study might have benefitted from more focus, and the comparatively loose structure of heuristic methodology perhaps did not help. However, it is also acknowledged that the struggle with focus has yielded genuinely unexpected knowledge.

Data collection

The volume of data collected was perhaps larger than the scope of this study required. However, the quality of data made this worthwhile.

Data analysis

The issue of focus may have complicated the analysis process. Additionally, the desire to avoid reduction or interpretation where possible may have resulted in a surfeit of ‘ideographic’ themes (Finlay 2009). The lack of clear steps of analysis in heuristic methodology (Moustakas 1990) – particularly in the area of reduction – may have contributed to this. This issue is explored further, below, in the section in which the methodology is evaluated.

Presentation of findings

The aim was to represent the participants’ experiences in a way that retained the person in the picture. However, the volume of data and its thematic breadth, combined with limited space, required curtailing the amount of detail extracted from individual depictions and exemplary portraits used to illustrate the composite depiction. Lack of space also required referring to participants as, for example, (A,B,C,D), rather than Participant A, Participant B, etc., which may have compounded a sense of impersonality. However, it is hoped that the biographies and extended verbatim that can be found in the individual depictions and exemplary portraits supplied in the appendix, mitigated this effect to some degree. The issue of reduction also affected the structure of the composite depiction. While effort was made to represent participants equally, some provided more detail about their experiences. This may have exerted a gravitational pull on the representation of the group as a whole toward the meanings of those individuals.

Reflection and bias

The study began with a critical disposition toward, what came to be termed, the medical meaning of ‘schizophrenia’. An attempt to balance this disposition with direct experience of the ‘other side of the story’ was made in the form of working as a manager in a mental health service for those with the diagnosis. As noted, the tension between these experiences has generated useful knowledge, and aided reflection.

There has been effort to be transparent about biases by talking about my own experiences, and how they might relate to the processes used in this study. Extra care was taken, for example, not to ignore findings that did not accord with my own ‘passionate concerns’ (Moustakas 1990:14). However, these concerns have inevitably directed my attention to some findings over others in this chapter’s discussion.

Such bias has inevitably played into my interpretation of the participants’ meanings as well. As Laing (1979) notes, we cannot help but place ‘our constructions or interpretations on “his” behaviour, as soon as we are in relationship with him’ (p31). For example, on the one hand (E) saw the voice of the psychic she heard as an attempt to create a more positive meaning of her ‘symptoms’ than a ‘disease concept’ (E:82:1). On the other, she thought voices were ‘a mixture of something supernatural and something technological’ (E:85:1). I would like to say that neither seems more ‘correct’, yet my own subjective framework gravitates toward the first meaning, which is no less an imposition of meaning than the medical one that has been critiqued here. Similarly, it would be naïve to believe participants’ personal meanings were exclusive of medical meaning. Their language was peppered with references to ‘super egos’, ‘splitting’, ‘personal constructs’ and ‘dissociations.’ What seemed key, however, was these terms appeared to be chosen, rather than imposed.

Finally, no evaluation of Heidegger can escape his ‘controversial involvement with Nazism’ (House 2010:113). There is not the scope here to examine this political and moral argument further, other than to acknowledge that the actions of Heidegger *the man* can seem glaringly antithetical to a philosophy that is used to examine the ethics of treatment. Leaving this to one side, we should also note that Heidegger’s position on meaning is just one approach, and just like any theory it is ‘self-confirming’ in the way it instructs one ‘to look at phenomena in particular ways’ (Silverman 2005:99). With these reflections in mind, it is important to note that while there has been an attempt to be transparent about the process of the ‘knowledge game’, this same game is inevitably being played here, even while I attempt to deconstruct it.

Evaluation of heuristic methodology

In Chapter 4, heuristic methodology was summed up in relation to five questions that are contested in phenomenology (Finlay 2009). The methodology was concluded to foreground researcher subjectivity reflexively; emphasise relationship over objectivity, and to take a postmodern, descriptive approach to ‘idiographic’ *meanings*, rather than a modernist explanatory approach to ‘normative’ *meaning*. This seemed to fit well with the aims of this study. However, five issues arose in the attempt to execute these aims.

Firstly, ‘[t]o what extent should interpretation be involved in our descriptions?’ (Finlay 2009:1) is not clear in heuristic methodology. In Chapter 4 it was noted that the methodology strives to represent the essence of the experience researched without losing sight of the person. In so doing, there seems to be an attempt to eschew some of the issues with modernism that arise in, for example, EP’s preoccupation with

reduction (Moustakas 1994:18-19). However, while the phases of heuristic research are clear (Moustakas 1990:27-32), and the structure for presenting findings is also clear (pp51-52), the method for ‘analysing’ and reducing data down to individual and composite depictions is not. Moustakas (1990) notes that ‘[o]rganizing and analyzing heuristic data during the immersion and incubation process may take many forms’ (p49). However, Clark, J. (1988), the example offered along with a brief description of the process that led to its findings, is neither a detailed nor definitive account. The description of ‘focussing’, which ‘determines the core themes that constitute an experience’ (Moustakas 1990:25), adds some detail to the process. However, its emphasis on the researcher’s ‘internal frame of reference’ (p12) to guide determination of themes relies on ‘intuition’ to make ‘immediate knowledge possible without the intervening steps of logic and reasoning’ (Moustakas 1990:23). This seems vague and may result in the researcher having to construct their own system of thematic ‘representation’, which may be EP-style reduction in all but name. Sela-Smith (2002), who specialises in using the method, notes in her review of twenty-five heuristic studies that the heuristic self-search, ‘*I-who-feels*’ approach to generating knowledge was often ‘replaced’ by an attempt to define the phenomenon (p71). Perhaps this illustrates the point. In the event, McLeod (2003) provided useful guidance for ‘categorising meanings’ and ordering ‘themes and patterns’ (p144), and this seemed compatible with Moustakas’ (1990) procedures of data analysis.

The emphasis on an internal frame of reference leads to a second issue, which is the potential lack of clarity between researcher and researched. While self-search is undoubtedly a key feature of the method, might the research itself become a solipsistic endeavour, in which the participants’ experiences are co-opted into the researcher’s?

In the case of this study, for example, might the participants' stories have been used as a way of telling my own?

This raises a third issue, which is verification. On the one hand, Moustakas (1990) places an emphasis on checking and re-checking the findings against the data to ensure that the presentation of the experience researched remains true, and that this process is 'enhanced' (although not required) by sharing meanings with participants (p33). On the other hand, '[t]he judgement of validity is made by the primary researcher, who is the only person in the investigation who has undergone the heuristic enquiry' from start to finish (Moustakas 1990:32). McLeod (2003) notes that all interpretive frameworks become caught up in a hermeneutic circle of knowledge (p87). For all the criticism here of closed circles of knowledge found in medical meaning, might heuristic methodology have merely helped me to get similarly caught up, and so compromise the judgement required for validity? In the event, it was decided to share the completed study, which would include both the participant's experiences along with some of my own³⁷. It was hoped this would be a more reciprocal approach, and would discourage me from taking a 'researcher who knows' stance. Moustakas' (1981) uses a similar approach to validation for his study on loneliness (p216).

The fourth issue is that a Rogerian conception of the researcher's internal frame of reference might fail to appreciate the postmodern condition of being a subject, in which this frame of reference cannot be considered to belong exclusively to the researcher alone. Therefore, while heuristic methodology might encourage the researcher to use their own story to access the stories of those researched, it may

³⁷ Participant feedback on what was shared can be found in the appendix.

allow the researcher to ignore the role that ‘indwelled’ (Polanyi 2009:16) cultural narratives play. That said, the emphasis on reflexive knowledge does give the researcher space to explore this area, and such ‘ontological-metaphysical’ exploration might have revealed something about ‘the so-called objective knowledge situation’ (Gelven 1989:65) being examined here.

The final issue concerns hermeneutics, and is connected to the last point, above. Moustakas (1990) states that in heuristic methodology only ‘co-researchers’ experiences with the phenomenon are considered’, not the hermeneutics of ‘human endeavours’, such as history, art and politics (p19). At the same time, he argues that ‘with virtually every question that matters personally there is also a social – and perhaps a universal – significance’ (p15). While this statement refers to the research question development stage, it nonetheless highlights a tension between the desire to use the personal in heuristic methodology, at the same time as attempting to screen out the agencies that the personal might be subject to. For example, Laing (1967) reminds us that the personal is inseparable from the political. Is it possible to speak about one’s story, and the story of participants, without taking the hermeneutics that these situations are situated within into account?

These issues add to the challenge of using a method that combines scientific enquiry, creative processes, ‘personal journey, testimony and analysis’ (McLeod 2003:84), with the consequence that ‘[i]t is no easy matter to construct a report which does justice to these different discourses’ (*ibid.*). This broad-church methodology may not have aided the struggle for focus in this study. However, overall, it does seem to have helped generate useful knowledge.

7.6. Suggestions for future research

In this study, what has been called personal meaning has been argued to be a key driver of recovery from ‘schizophrenia’. It was argued that medical meaning intervening care might obstruct personal meaning, whereas an anticipating care approach might be one way of facilitating it. This proposition could be explored further in three areas.

The first area would involve specifically researching how these issues might play out in psychotherapy. Three types of study could be useful. 1) A study that examines the structure of NICE recommended psychotherapies and their outcomes in relation to these issues. This would take the primary form of a literature review. 2) (G) suggested interviewing the participants in this study at a future date to explore what has changed in the process of continued psychotherapy. This would add a valuable longitudinal aspect to what has been researched here, and would allow for interviews to focus on how the qualities of helpful, and unhelpful psychotherapy might relate to meaning and Heidegger’s modes of care. 3) A funded trial to examine these issues with a greater number of participants. However, considering the economics of research, which are often geared to supporting medical meaning, funding might be hard to come by.

A second area would be in the intersection between science and art, which has played an important role in this study. As mentioned above, the learning from this study has been incorporated into a parallel fictional film, and the attempt to represent these issues dramatically will throw up new thinking, which would hopefully feed back into the first area of suggested research, above.

Finally, during the process of this study, parallels between mind and physical environment have emerged, which Heidegger's (2008) concept of 'environmentally' encountered *Dasein* (p155) seems to reflect. This has led to me developing a body of work that explores these parallels further under the umbrella of 'the mind environment', a concept that is briefly touched on at the close of this study. One intriguing parallel is modernity's role in the destruction of the natural environment, and how, what might be loosely described as postmodern discourses, have influenced the environmentalist movement. It is hoped that further research into this area will be fruitful.

7.7. Conclusion

The empirical aim of this study was to explore the psychotherapeutic experiences of those with a 'schizophrenia' diagnosis. Free-ranging, conversational interviews yielded rich detail about the phenomenon, which suggested that the participants' experiences had been characterised by a struggle with meaning. The epistemological aim of this study was to deconstruct the knowledge underlying the 'schizophrenia' diagnosis, and Heidegger, Laing and critical clinical discourses were used toward this end. The arguments raised in this deconstruction were then applied to the knowledge gleaned empirically, leading to a three-pronged conclusion. Firstly, 'schizophrenic' breakdown might be described as a crisis of personal meaning, and addressing this meaning seems to be an important driver of recovery. Secondly, in failing to take this crisis of meaning into account the knowledge underpinning the medical meaning treatment of 'schizophrenia' is itself in crisis. Thirdly, when these two crises collide within a medical approach to care that intervenes, the resultant domination of personal

meaning may produce a third crisis – that of a long-term ‘broken self’ (Bollas 2013), or what DSM calls the ‘acute’ phase (APA 2005:307) of ‘schizophrenia’.

It has been noted that overturning the medical paradigm, which may unwittingly provide the conditions for the second and third aspects of this crisis, constitutes a ‘massive and multifaceted task’ (Rapley *et al* 2011:5). In 7.3. a number of suggestions were made for opening this paradigm to critical thought and what is found in practice. In this concluding section, returning to the metaphor used in the creative synthesis (6.4.), a brief examination of the wider ‘environmental’ picture might help us think about this task. Two areas seem particularly obstructive.

The first is the prevailing culture of objective science in mental health, in which the study of substances is seen as inherently more ‘scientific’ than the study of meaning. Not long after Bleuler first coined the term ‘schizophrenia,’ he noted with regret that colleagues who were perceived to not focus on ‘physical explanations’ were reproached for being ‘unscientific’ (Bleuler *in* Barham 1995:27). Nearly a century later this attitude seems little changed, as this extract from Noll’s (2000) *Encyclopaedia of Schizophrenia* suggests.

[A]dvances in the brain sciences have refuted all the major claims of psychoanalysis.

Psychoanalysis is now regarded as a pseudoscience and has no place in ethical psychiatric practice (p39).

Noll grounds this critique in structural evidence derived from PET scans, MRIs and rCBFs (regional blood flow measures), which showed that ‘auditory hallucinations were not “imaginary” (or products of some vague Freudian “superego” or “defence

mechanism”) but due to the activity of a specific region of the brain’ (p39). This argument speciously sets ‘scientific’ study of the brain against ‘unscientific’ conceptual models of mind. As Solms & Turnbull (2011) remind us, ‘[a]ll of psychology is ultimately just model-building of one sort or another’ (p136). In this sense, a super ego is no more visible on a material level than a cognitive schema, which belongs to the same medical meaning in which Noll grounds his argument.

In the second area are the vastly profitable industries with which this culture is symbiotically enmeshed. For example, Law (2006) estimates that ‘the combined profits of the ten pharmaceutical companies in the 2002 Fortune 500 (\$39.9 billion)’ were more than the profits for all the other 490 listed businesses put together (\$33.7 billion). With APA board members freely able to sit on pharmaceutical company boards, a worrying relationship has been noted between the drive to create new markets for drugs and proliferating psychiatric diagnoses that ‘describe’ the illnesses these drugs purport to treat (Law 2006, Breggin 2008, Whittaker 2010). The insurance industry (worth an estimated \$72 billion in the mental health sector) then validates these diagnoses because claims cannot be made without them (Bentall 2005:57).

While psychotherapy has a less obviously patentable ‘end product’, modalities that are linked to this vast economic machinery and the promises offered: ‘observable faulty mechanisms’, ‘prescribed interventions’, ‘symptom management’ etc., are naturally favoured. By way of example, the psychotherapeutic advisory input to NICE’s NCCMH panel is overwhelmingly CBT orientated, with individuals attracting up to £6 million in funding for their research. In this sense, both the privileging of knowledge that claims objective certainty, and the economic interests that this

attracts, inevitably skew the provision of psychotherapy for those with the diagnosis toward a medical meaning intervening care approach.

Bracken (2002) likens the objective focus on mechanisms to explain the mind to a person walking at night by the light of torch, whose beam misses the environment surrounding its narrow path (p5). The powerful forces briefly touched on here might serve to confine that beam, rather than allowing the wider environmental picture to be illuminated. Returning again to the metaphor used in the creative synthesis, in the same way that the *seen* environment does not result from just one agent (rocks, say) but rather the interaction of a complex environmental system of diverse agents (and the corresponding conceptual models that are used to study them), what might be called the embodied ‘mind environment’ seems a similarly complex interaction between the material and measurable (genes and neurons), and the non-material and un-measurable (experience and culture). Rather than condemning what is considered un-measurable to the ‘unscientific’ dustbin, Heidegger’s (2008) ‘environmentally’ encountered *Dasein* may help us think about such an interaction between the two. This ecological metaphor finds a parallel in, for example, Totton’s (2012) rejection of ‘outcome-orientated therapy’ in favour of an approach that sees the therapy relationship as ‘an eco-system’ which is ‘embedded within a greater eco-system’, and which places meaning-making at its heart (Brazier 2012:85). The task that Rapley *et al* (2011) imagine seems Copernican in scale, and the arguments raised here may be equally heretical to some. The now mainstream environmental movement was once suppressed for challenging modernist assumptions about interactions between man and nature (and related economic interests). Perhaps what we could call ‘mind environmentalism’ is merely behind the ‘paradigm’ curve.

In a study that argues the importance of personal meaning, the most fitting way to close is with the experience of one of its participants. Like Lauveng (2012), who believes that '[o]nce you've learned [recovery], it's hard to forget' (p166), (C) realised that while the struggle to give her experiences personal meaning was painful, this new self-knowledge meant she could never go back to being 'schizophrenic' (C:31:2-38:2).

Appendices

**Approval to carry out research from University of Roehampton Ethics
Committee**

From: <L.Rochard@roehampton.ac.uk>
Date: 3 September 2010 13:08:49 GMT+01:00
To: <tom@tomcotton.co.uk>
Cc: <D.Loewenthal@roehampton.ac.uk>,
<Jan.Harrison@roehampton.ac.uk>, <L.Slade@roehampton.ac.uk>
Subject: **Ethics Application - COTTON, Tom**

Dear Tom,

Ethics Application (Student)

Applicant: Tom Cotton

Title: An exploration of whether psychotherapy is helpful or not for those who have received a diagnosis of schizophrenia.

School: HALS

I am pleased to confirm that the above application has been approved by Chairs Action on behalf of the Ethics Board. We do not require anything further in relation to this application.

Many thanks,

Lemady

Lemady Rochard
Research Policy Officer
Research and Business Development Office
208 Grove House, Froebel College
Roehampton University
Roehampton Lane
London
SW15 5PJ

T: +44 (0)20 8392 3256
E: L.Rochard@roehampton.ac.uk

Further information on service user networks approached

The Hearing Voices Network (HVN)

I first came into contact with the Hearing Voices Network in the process of developing Cotton (2010). This is a national network with offices distributed across the UK, which supports service-users who have experiences of hearing voices, and received diagnoses such as 'schizophrenia'. Regional networks are often managed and run by ex-service users and offer information, support and understanding to people who hear voices and those who support them. The high concentration of service-users with a 'schizophrenia' diagnosis within the network made it an ideal choice as a source of recruitment.

www.hearing-voices.org

The National Survivor User Network (NSUN)

This is a national network of service-user groups, which promotes service-user led research. Their aim is to create a network which will engage and support the wide diversity of mental health service users and survivors across England in order to strengthen the user voice, as well as brokering and facilitating access between policy makers and service users. The NSUN's enthusiasm for taking part in research that helps give service-users a voice, made them a natural choice in terms of recruitment for this study. During the process of participant selection I was in contact with Amma Djan from NSUN's head office, who was supportive of potential recruitment from the organization. The head office has a room where interviews may be conducted and it was discussed as a possible site for interviews to take place if a neutral location (other than the participant's home) were to be required.

<http://www.nsun.org.uk/>

Intervoice

Intervoice is an online forum that connects the international hearing voices movement. Intervoice promotes self-empowerment for voice hearers and 'focuses on facilitating relevant assistance and solutions that improve the life of voice hearers in the knowledge that these methods have been co-developed by voice hearers and professionals' (Intervoice website). At the time of approaching participants, Intervoice was hosted by the Rachel Waddingham, who I had already discussed the research with in relation to the involvement of the Hearing Voices Network.

<http://www.intervoiceonline.org/>

Letter of approach to NSUN

Dear Sarah

Thank you for your interest in my psychotherapy qualitative research study: **An exploration of whether psychotherapy is helpful or not for those who have received a diagnosis of schizophrenia.**

I have attached the following documents for further reference:

- 1) Letter of approach to potential research participants.
- 2) Research briefing form
- 3) Participant consent form
- 4) Research debriefing form

In order to comply with the Roehampton University Ethics Board's requirements for this piece of research, I would like to ask you if it might be possible to email me confirming the following:

- 1) The suitability of members of your support network for taking part in this research study.
- 2) The availability of a room at your offices, or at one of your regional network offices (depending on the location of potential participants) where interviews could take place.
- 3) In the eventuality participants were to become distressed during the course of the interview, a member of staff would be present in the building to offer support.
- 4) If interested members of your support network would prefer to be interviewed in an alternative location, that you will be able to supply a letter or email approving their suitability for this.

Many thanks indeed for your help with this research project, I look forward to hearing from you.

Best wishes

Tom Cotton

02/08/2010

6th August 2010

Re: Psychotherapy research, examining the experiences of people who have received a schizophrenia diagnosis

Dear Tom,

I have received the information for your research study. I would like to confirm that NSUN is able to support this research. I can confirm the following:

1) Suitability of NSUN members taking part in this research study

The National Survivor User Network is a network of over 800 individuals and groups across England. Opportunities to engage and get involved in studies such as this are promoted through weekly bulletins. Involvement is on a self selection basis, and then (where appropriate) a facilitated and supported recruitment process. Membership is from a wide diversity of people who have a range of mental health experiences and conditions. We would need to be clear where the interviews are taking place (if there is a limit to travel) and what the terms of involvement are regarding payment or reimbursement of expenses.

2) Availability of a room at our main office or a regional office

We do not have a private space to meet at the NSUN office but we would be willing to make arrangements at a suitable venue that is convenient and accessible to the interviewer and interviewees. This may however incur rental costs.

3) Presence of a member of staff in the building

NSUN would negotiate having a presence that is appropriate and supportive at the interviews. This may be a paid member of staff, a volunteer or a family member or friend of the interviewee.

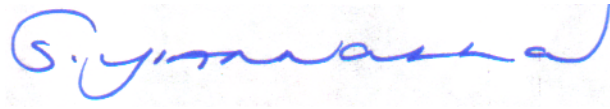
4) Providing a letter or email of support indicating a member's suitability to be interviewed at an alternate location of their choosing

NSUN is not in the position to approve the suitability of an alternative location. This would need to be negotiated between the interviewer and interviewee. NSUN would assist in finding a suitable location that meets the needs of the interviewer if required.

On the debriefing form NSUN should be the **National Survivor User Network**. It may helpful to also include the Patient Opinion site <http://www.patientopinion.org.uk/>

I look forward to hearing from you.

Kind regards



Sarah Yiannoullou
NSUN Manager

Mobile: 07778 659 390
Office: 0845 602 0779

27-29 Vauxhall Grove, Vauxhall, London, SW8 1SY

Registered charity no.1135980 Company Registration no.7166851

Response from HVN

From: Rachel Waddingham <RWaddingham@mindincamden.org.uk>

Date: 5 July 2010 12:57:19 BST

To: Tom Cotton <tom@tomcotton.co.uk>

Subject: RE: Psychotherapy research project

Dear Tom,

Thank you for sending me the details of your research study. I would like to take this opportunity to confirm that you have liaised with me whilst developing the way in which this research may be supported by the London Hearing Voices Network at Mind in Camden. Further to these conversations I can confirm the following:

1) **Suitability of the members of LHVN for the proposed research** The London Hearing Voices Network is a network of over 40 Hearing Voices Groups across Greater London. As such, the group facilitators and host organisations are members of LHVN, whereas members themselves are not. Consequently I am unable to comment on individual group member's suitability for the research. Individual suitability is something which must be determined by the person themselves, in conjunction with yourself and the group facilitator who will know them well. Initial conversations with the person, and careful attention to the process of gaining informed consent, will support this.

Speaking more generally, my experience of the people who attend groups within our network – and those who facilitate these groups – is that the people to step forward to take part will be those who feel most comfortable talking about their experiences and are interested in the research topic. The groups themselves help members develop confidence in exploring their own experience and promote personal choice in deciding what to share, and what not to share with others. This, then, enhances their ability to make their own choices as to whether or not to take part in research. I confirm that I understand the purpose of the research, and the way in which you intend to carry it out, and see no reason why members of Hearing Voices Groups within our network should be deemed unsuitable for it per se. Having said that, it is important to give proper care and consideration to the informed consent process to ensure that potential participants have all the necessary information and a chance to think through any potential concerns either you or they have about them taking part.

2) **Availability of a room at our main office or a regional office** Where necessary, we are happy to offer one of our rooms for the interview. Where the person interviewed is a member of a group within our network not based at Mind in Camden, they may be happier to meet you at the organisation which hosts their group. As these are independent organisations I cannot guarantee rooms on their behalf, however from prior experience of research

being conducted within the network they are usually very willing to accommodate this for the benefit of their members. If necessary, I am happy to help facilitate this.

3) Presence of a member of staff in the building

If you conduct an interview at Mind in Camden, there will always be a member of staff in the building. They will be able to offer some support if necessary. However, in line with the ethos of our groups, it is more appropriate if you could spend some time speaking with the participant prior to the interview to establish what support they would find most helpful if the interview did trigger distressing feelings. This support may come from a friend, family members, support worker, CPN or they may have sufficient internal resources to manage their own distress and not require additional help or find attempts to secure this as patronising. I would suggest that you encourage the person to access the supportive person they identified, should they become distressed – thus refraining from taking control or power away from them by seeking this person's help on their behalf. Where necessary, offer to support them to do this or do this on their behalf. Given the range of personal situations, experience with mental health services and levels of resilience within members of Hearing Voices Groups it is most helpful if you do not make assumptions in this area and are led by the person themselves.

If you conduct an interview at the base of one of the groups within our network you should liaise with them directly about the presence of a member of staff who is able to offer support should it be necessary. If the participant uses their services then they are generally happy to do this. If they are a member of staff or facilitate the group themselves, please be aware that they may not feel it appropriate to access support in their workplace and this wish should be understood and adhered to. As with non-members of staff – the most helpful form of support may exist outside of the workplace.

4) Providing a letter or email of support indicating a member's suitability to be interviewed at an alternate location of their choosing

Given the emphasis of personal choice and empowerment of the Hearing Voices Groups and our network, I would feel extremely uncomfortable with providing a letter to confirm that the person has the ability to exercise this choice. As someone who has personally been diagnosed with schizophrenia, I can attest to the way in which a member may experience this as patronising and/or disempowering (although I acknowledge that the request is made with the best of intentions). If a participant requests an alternative venue, a way forward could be to discuss the suitability of this with them and make sure that you talk through the pros and cons of this choice with them. Any letter of suitability should, in my opinion, come from the individual themselves in line with their ability as an adult to make an informed choice. Respecting their ability to do this is more likely to result in a productive interview in which they are able to feel safe and supported. For example, if they have a partner or friend they trust they may choose to have the interview in a place in which they will be able to offer support rather than a member of staff.

Additionally, I would also like to suggest some additions to the debriefing sheet which people may find helpful. Please include more options for phone support (Samaritans, Rethink and MindinfoLine), the updated HVN details (0114 271 8210) and details of advocacy organisations which may be of use if they find that through the interview they feel dissatisfied with the support they have received in the past, or currently receive, and would like support to take this further.

You might also like to include the details of the Mental Health Forum (www.mentalhealthforum.net) which runs a Hearing Voices forum in partnership with Intervoice.

I am pleased that you are progressing with your plans to carry out this interesting and, hopefully, beneficial research into what is a largely unexplored area. From my own personal experience as someone who has received a schizophrenia spectrum diagnosis, and as manager of the London Hearing Voices Network, I believe that it meets a growing need to explore the range of ways people distressed by voices, visions and unusual thoughts can be supported and, perhaps more importantly, their experience of this support (both positive and negative).

If you, or your supervisor, have any questions relating to the above – please get in touch.

Warm regards

Rachel Waddingham

Rachel Waddingham

London Hearing Voices Project Manager

Mind in Camden

Email: rwaddingham@mindincamden.org.uk | **Tel:** 020 7625 9042

Post: Crossfields Centre, 8 Fairhazel Gardens, London, NW6 3SG

Check out our new website for young people (aged 12-18) who hear, see or sense things that others don't (www.voicecollective.co.uk)

Research summary for peer support networks to distribute

Research study exploring the experiences of people who have received a diagnosis of schizophrenia and whether psychotherapy has been helpful or not

This qualitative research study aims to represent participants' experiences as accurately as possible, and to raise the profile of these experiences in what is an important, yet under-represented area.

If you have received a diagnosis of schizophrenia and have had experiences of psychotherapy – this could include, for example, counselling, clinical psychology, CBT, psychoanalysis, or family therapy, amongst others, and you would like to talk about your experiences as a participant in this research study, then I would very much like to hear from you.

Tom Cotton, psychotherapist.
Roehampton University
Email: tom@tomcotto.co.uk
Mobile: 07799262956

Researcher: Tom Stapleton - Cotton
E-mail: tom@tomcotton.co.uk
Tel: 07799262956

Supervisor: Dr. Julia Cayne
E-mail: J.Cayne@roehampton.ac.uk
Tel: 0208 3923000 ext 5788

Date

Dear Sir/Madam,

I am a postgraduate student, currently studying for a Psych-D in Psychotherapy and Counselling in the School of Human and Life Sciences department of Roehampton University.

As part of my studies, I am carrying out a qualitative research study, entitled:

An exploration of whether psychotherapy is helpful or not for those who have received a diagnosis of schizophrenia

This study aims to increase the understanding of the experiences of people who have received a 'schizophrenia' diagnosis, and in particular, whether psychotherapy has been helpful or not. In the context of this research, the term 'psychotherapy' applies to any kind of talking therapy that participants might have encountered, regardless of whether it has been delivered by a clinical psychologist, a psychotherapist, or a counsellor.

- I would like to invite you to be a participant in this study by taking part in a one to one interview.
- The interview will last approximately one hour and will take place in a private space provided by the support service who distributed this letter to you.
- The interview will be audio recorded for transcription and then the recording destroyed. All identifying information will be removed during transcription. This is to guarantee your anonymity, confidentiality and privacy as a participant.

- If emotionally difficult material arises during the course of the interview, there will be time at the end of the interview to process this together. Should you wish to discuss this in greater depth with a form of more specialist support than I'm able to offer, we can discuss options for accessing this support.
- Participation in this study will not affect in any way support you may be currently receiving through the organisation who distributed this letter to you.
- This research study is not funded, therefore, unfortunately I am not able to offer a fee in return for taking part. However, I will be able to refund your travel expenses if you are travelling to the interview from within the London area, up to a maximum of £10. This arrangement will be subject to discussion should you be interested in taking part.

If you are interested in taking part in this research study, or would like to know more about the study, please don't hesitate to contact me on:

E-mail: tom@tomcotton.co.uk

Tel: 07799262956

Yours sincerely,

Tom Stapleton - Cotton

RESEARCH BRIEFING FORM

Researcher: Tom Stapleton - Cotton
E-mail: tom@tomcotton.co.uk
Tel: 07799262956

Supervisor: Dr. Julia Cayne
E-mail: J.Cayne@roehampton.ac.uk
Tel: 0208 3923000 ext 5788

Title of research project:

An exploration of whether psychotherapy is helpful or not for those who have received a diagnosis of schizophrenia.

My name is Tom Stapleton – Cotton and I am studying for a Psych-D in Psychotherapy and Counselling at Roehampton University. My supervisor for this project is Dr Julia Cayne.

The experiences of people who have received a schizophrenia diagnosis are under-represented in research literature and I am interested in adding to existing understandings by exploring these experiences, in particular, in relation to whether psychotherapy has been helpful or not. In the context of this research, the term ‘psychotherapy’ applies to any kind of talking therapy that participants might have encountered, regardless of whether it has been delivered by a clinical psychologist, a psychotherapist, or a counsellor.

This is a qualitative research study, which seeks to convey the content of participants’ experiences.

Interviews will be confidential and conducted one to one in a space provided by the support organisation which distributed my letter of approach to you. Interviews will last approximately one hour and will be audio recorded. This recording will then be transcribed. The transcribed data will be made anonymous to protect your identity and the original audio recording will be destroyed for the same purpose.

If you feel uncomfortable with any of the interview questions, you are under no obligation to answer them and you can stop the interview at any time.

After the completion of the interview you may also withdraw the content of your interview from the study. However, if you do decide this is appropriate,

there will be a deadline for withdrawal to ensure that your interview data is not assimilated into the completed study. This deadline will be 10/02/12.

Participation in this study will not affect in any way support you may be currently receiving through the organisation who drew your attention to this study.

It is hoped that by undertaking this research, the experiences of people who have received a schizophrenia diagnosis, particularly in relation to whether psychotherapy has been helpful or not, will be more widely appreciated and understood.

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the researcher. However if you would like to contact an independent party please contact the Dean of School (or if the researcher is a student the Director of Studies.)

Director of Studies Contact Details:

Prof. Del Loewenthal
Director of the Research Centre for Therapeutic Education
Convener, Doctoral Programme in Psychotherapy, Counselling and
Counselling Psychology
School of Human and Life Sciences
Roehampton University
Whitelands College
Holybourne Avenue
LONDON
SW15 4JD
Tel: 0208 392 3615
Email: d.loewenthal@roehampton.ac.uk

Dean of School Contact Details:

Michael Barham
School of Human and Life Sciences
Roehampton University
Whitelands College
Holybourne Avenue
LONDON
SW15 4JD
Tel: 0208 392 3617
Email: b.barham@roehampton.ac.uk.

Thank you for your time.

ETHICS BOARD

Debriefing Information

Researcher: Tom Stapleton - Cotton
E-mail: tom@tomcotton.co.uk
Tel: 07799262956

Supervisor: Dr. Julia Cayne
E-mail: J.Cayne@roehampton.ac.uk
Tel: 0208 3923000 ext 5788

Title of research project:

An exploration of whether psychotherapy is helpful or not for those who have received a diagnosis of schizophrenia.

Thank you for taking the time to participate in this research study.

I'm aware that during the course of this interview, we may have spoken about some difficult experiences. I would now like to offer you some time to talk about anything that may have come up for you in what we have spoken about.

- Would you like some time to talk about anything that came up during the course of this interview?
- Do you have any further comments or questions before we end for today?
- If you think of anything later, I'll be available on email or telephone to answer any questions that you may have about this research. My contact details are on the following page.
- Should you wish to discuss in greater depth any issue that came up for you during the course of this research with a form of more specialist support than I'm able to offer, the following may be useful:

If our interview has raised issues about support you have received in the past, or are currently receiving, you may like to contact a patient advocacy organization and discuss this further. The following organizations might be useful. **Rethink**: 0207 840 3188

www.rethink.org/contact_us.html, **Mind Freedom**
www.mindfreedom.org/, **Mindinfo**line: 0845 766 0163
www.mind.org.uk/help/information_and_advice, **The National Service**
User Network: 0207 820 8982 www.nsun.org.uk/ and the **Patient**
Opinion website: <http://www.patientopinion.org.uk/>

If appropriate for you, the **Hearing Voices Network** has a range of support groups across the UK. A list of groups can be found at www.hearing-voices.org/index.html or you can call them on 0114 271 8210. Alternatively, **Intervoice**, the international community for hearing voices, offers an online support service. Their website can be found at www.intervoiceonline.org/, or they can be emailed at: admin@intervoiceonline.org. **The National Service User Network** helps connect service-user groups with individuals and may offer more general support. They can be found at www.nsun.org.uk/, or you can call them on: 0207 820 8982.

For telephone support, the following organizations may be of use:

Samaritans: 08457 90 9090

www.samaritans.org/talk_to_someone.aspx

Rethink www.rethink.org/contact_us.html or 0207 840 3188, and

Mindinfoline www.mind.org.uk/help/information_and_advice, or 0845

766 0163. Alternatively, the **Mental Health Forum**

(www.mentalhealthforum.net) runs a **Hearing Voices** online forum in partnership with **Intervoice**.

- For more specialised, individual support, The **British Association for Counselling and Psychotherapy**: 01455 883300, <http://wam.bacp.co.uk/wam/SeekTherapist.exe?NEWSEARCH> and the **United Kingdom Council for Psychotherapy**: 020 7014 9955 www.psychotherapy.org.uk/find_a_therapist_search.html both have lists for therapists in your area.

Declaration:

I confirm that the interview was conducted in an ethical and professional manner and that I am happy for the research to proceed using my material.

Participant

Name

Date

Participant ID number

Signed

Researcher

Name

Date

Signed

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the researcher. However if you would like to contact an independent party please contact the Dean of School (or if the researcher is a student the Director of Studies.) Contact details for both the Dean of School and the Director of Studies can found on the next page.

Director of Studies Contact Details:

Prof. Del Loewenthal
Director of the Research Centre for Therapeutic Education
Convener, Doctoral Programme in Psychotherapy, Counselling and
Counselling Psychology
School of Human and Life Sciences
Roehampton University
Whitelands College
Holybourne Avenue
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Tel: 0208 392 3615
Email: d.loewenthal@roehampton.ac.uk

Dean of School Contact Details:

Michael Barham
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SW15 4JD
Tel: 0208 392 3617
Email: b.barham@roehampton.ac.uk.

ETHICS BOARD

PARTICIPANT CONSENT FORM

Researcher: Tom Stapleton - Cotton
E-mail: tom@tomcotton.co.uk
Tel: 07799262956

Supervisor: Dr. Julia Cayne
E-mail: J.Cayne@roehampton.ac.uk
Tel: 0208 3923000 ext 5788

Title of research project:

An exploration of whether psychotherapy is helpful or not for those who have received a diagnosis of schizophrenia.

This is a qualitative research study that explores the experiences of people who have received a diagnosis of schizophrenia, in relation to whether psychotherapeutic intervention has been helpful, or unhelpful. In the context of this research, the term 'psychotherapy' applies to any kind of talking therapy that participants might have encountered, regardless of whether it has been delivered by a clinical psychologist, a psychotherapist, or a counsellor.

A total of eight participants are being sought for this study. Interviews with participants will be confidential and conducted one to one in a space provided by the support organisation which distributed my letter of approach to you. Interviews will last approximately one hour and will be audio recorded. This recording will then be transcribed. The transcribed data will be made anonymous to protect your identity and the original audio recording will be destroyed for the same purpose.

If you feel uncomfortable with any of the interview questions, you are under no obligation to answer them and you can stop the interview at any time.

After the completion of the interview you may also withdraw the content of your interview from the study. However, if you do decide this is appropriate, there will be a deadline for withdrawal to ensure that your interview data is not assimilated into the completed study. This deadline will be 10/02/11.

Participation in this study will not affect in any way support you may be currently receiving through the organisation who drew your attention to this

study.

Consent statement:

- I confirm I have had the opportunity to consider the information, and have had any questions asked answered to my satisfaction.
- I understand that my participation is voluntary and that I am free to withdraw from this study at any time.
- I understand that I may refuse to answer any questions at any time.
- I understand that the information I provide will be treated with absolute confidentiality and that my anonymity will be protected.
- I understand that should I wish to withdraw after I have completed the interview I can email the researcher and my data will be destroyed and removed from the research database.

I confirm that I understand the consent statement and agree to take part in the proposed research project.

Participant

Name

Date

Participant ID number

Signed

Researcher

Name

Date

Signed

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the researcher. However if you would like to contact an independent party please contact the Dean of School (or if the researcher is a student, the Director of Studies.) Contact details for both the Dean of School and the Director of Studies can found on the next page.

Director of Studies Contact Details:

Prof. Del Loewenthal

Director of the Research Centre for Therapeutic Education
Convener, Doctoral Programme in Psychotherapy, Counselling and
Counselling Psychology
School of Human and Life Sciences
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Roehampton University
Whitelands College
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SW15 4JD
Tel: 0208 392 3617
Email: b.barham@roehampton.ac.uk.

TRANSCRIPTION RULES

Researcher: Tom Stapleton - Cotton
E-mail: tom@tomcotton.co.uk
Tel: 07799262956

Supervisor: Dr. Julia Cayne
E-mail: J.Cayne@roehampton.ac.uk
Tel: 0208 3923000 ext 5788

Title of research project:

'An exploration of whether psychotherapy is helpful or not for those who have received a diagnosis of schizophrenia'

TRANSCRIPTION RULES

All interview text should be faithfully transcribed. Meanings can be greatly changed by an alteration in tense, missing words, etc. Therefore, no approximation, or summarisation should be used. There may be exceptions, such as:

- 1) 'Ums', 'Ers' and 'ahs' are usually peppered throughout ordinary conversation and these should be ignored. However, where they seem integral to a speaking style (i.e. someone who hesitates a lot), as sense of this hesitation should be retained.
- 3) Pauses longer than approximately 2 seconds should be represented by....
- 4) Mumbled, inaudible or gestured words should be contained inside non-italicised brackets, for example (*inaudible*). Italicised bracketed words represent comments on the text.
- 5) Incomprehensible, or unfamiliar words should be represented as (*unclear*).
- 6) Missing words that may have been gestured, or just missed out, should be represented as, for example, (With), or (and). I.e. bracketed un-italicised words represent the words of the participant that are missed out or intoned and replaced the give the text a better sense where it may be unclear to the reader.
- 7) Double quotation marks (") represent where the participant is referencing a conversation or thought.
- 8) Single quotation marks (') are used for when a participant is placing a comment in inverted commas, for example, when the reference is ironic, or they don't agree with the statement.
- 9) Words in italics without brackets represent words that the participant may have placed particular stress on to make a point, or to emphasise a word.

10) All names and places are anonymous. However, in order to reduce confusion, names and places may be represented by, for example, B**** where they appear more than once in the text. The only exception to anonymised names, are the names of people who are prominent figures in the voice hearing movement.

TIMECODE REFERENCE

Because of the research method being used, I will need to refer back to original audio and compare this with the written transcription. In order to facilitate this, each paragraph (this could be a new statement from research or interviewee, or paragraphs within a very long piece of dialogue) should start with the audio's **timecode** for ease of reference.

TRANSCRIPTION ETHICS

The research data contained in the interviews is confidential, sensitive information and should not be discussed with third parties.

All interview data will be made anonymous in the research study report.

Retaining the flow, spirit and meaning of the material was a premium concern. All transcripts were read through by me and corrected and checked against the original data.

Participant A – individual depiction

Now in his early forties, (A) had three experiences of psychotherapy at different stages in his life. The first was when he was in his twenties, some time after experiencing a psychotic breakdown. He was first hospitalised around this time, and the primary form of treatment was medication. This helped dampen down the intensity of the voices, but also had severe side effects, like muscular spasms and his eyes rolling back into his head. He was given a short course of CBT at around this time, but he felt that the method made assumptions about what was normal, and what was pathological, and that he had little opportunity to explore his experiences. Because he made it clear to his care team that he didn't want more CBT, he was told that the NHS had nothing more to offer him.

(A) seemed to spend some time drifting after that, trying to work, because that helped, but struggling with it because of the medication he was taking. He began working with a clinical psychologist who was interested in working with voices, which was helpful, but it was intermittent, and short-lived. (A) met his wife around this time, and their developing relationship encouraged him to explore what he felt were underlying problematic issues in his life. He began working with a counsellor, but told him he didn't want to talk about schizophrenia in any way, rather, he wanted to help him sort out his life. (A) felt the counsellor helped him greatly, by helping him to explore what was going on in his life and the emotional issues that were related to these events. He found this work reduced his anxiety, and this reduced the frequency and negative appearance of voices. However, he wasn't able to speak about his experiences of being bullied at school, which he recognised at the time had been a traumatic experience, because doing so on one occasion had exacerbated his voices.

(A) became active in HVN and started facilitating groups. His interest in HVN seemed to come at a time when he was starting to look more deeply at the meaning of his symptoms, and this led to the third phase of psychotherapy, this time with a Lacanian psychoanalyst, who satisfied (A)'s interests in linguistics, philosophy and social theory. In this therapy work, (A) felt able to explore complex issues in his family, and how these played into both the initial breakdown he experienced, as well as the psychotic symptoms he experiences. For example, he felt his mother's love was highly conditional and that she was untruthful about what she really felt, which left him unable to read other people's facial expressions. Attempting to explore these issues with his family led to conflict, and he was singled out as being problematic. Later, being diagnosed with schizophrenia, and having this explained as a genetic problem, reinforced the feeling that he was the problem in the family.

(A) was also finally able to start addressing his school experiences, which had been traumatic for a number of reasons. (A) was sent to boarding school at an early age, but was a year younger than the rest of his year and was bullied for being physically underdeveloped. He was also bullied for coming from a working class background, and his principal bully was a friend who was the only other boy in the school to come from a similar background. (A) felt that addressing these experiences, combined with finding medication that had less side effects, has led to him rarely hearing voices in one to one conversation, except in arguments. (A) is married with two small children.

A1) Experienced a first phase of trauma in childhood and early adolescence

Boarding school was traumatic

Participant didn't fit in at boarding school and felt the system was brutal

(A:97:7) my dad was a shop-fitter, and I went to a school that was a school of politicians' sons and lords and corporate business people... (A:103:1) basically- think of Lord of the Flies, where all the kids are left together – that was how the school was run, so the eldest boys policed the younger boys and made them behave and all that sort of stuff, and so the idea was that you would aspire to become a prefect, so that you could dish out the punishments. I mean, just before I'd left, they'd only just stopped allowing the 6th formers to cane the other boys.

Participant was a year younger than his peers and was bullied for being underdeveloped

(A:93:2) I started at the age of 12 in a year with other kids starting at the age of 13...

(A:94:1) Pushy parents.... (A:94:2) I went through puberty there, but of course I was a year – I was a late developer and I was a year younger than the guys in my year, so lots of shit for supposedly being underdeveloped.

Participant bullied by a boy whose similar working class background also made him an outsider in the school

(A:97:1 - A:97:10) *There was one other boarder who came from a working class background, who participant identified with, but who then bullied him.* (A:97:10) He felt out of place, as I did. But he was older and harder, tougher, so they picked on me. I mean the weird thing- weird shit happens as well, which had affected my trust, was later we were given studies and, and another guy turned up later who bullied me as well and the two of them fought over me to share with them, because they couldn't stand anyone else (*laughs*). So I had a whole load of issues to do with that... (A:98:1) they ended up- both of them ended up getting expelled for whipping another kid in the showers... (A:99:1) With coat-hangers. Naked. So, they were... fucked up... I understand that they were really weren't happy there (*laughs*) – I wasn't happy there because of them either... (A:102:4) but they were then expelled and my life got better...

Became confused about identity in early adolescence

Felt guilty about taking on public school identity/sense of superiority

(A:112:3) there's other things as well that I felt guilt about... I remember going to chapel in the morning and I'd have some reverent preaching to me that I was some cream of society and that I was the top 1 percent, and all this sort of stuff, which I – 'cos I didn't fit in, 'cos I was petty bourgeois done good, you know, shop-fitter's son – started taking on board, "Wow! (I) must be great".

Become a bully and felt guilty

(A:113:1) I went on a school skiing trip and there was another school there, and I went in their room – I used to get really drunk 'cos I hated it there at school. So I go really drunk and went in there, sort of- I suppose I really wanted to be friends with them, but instead, I did the same things the other boys did and tried to bully them – but a whole *roomful* of them... (A:113:7) I was going "Oh, yeah, public school people are just naturally superior" and all this stuff. And I've never seen the hate in people's eyes. Never since it since... (A:113:8) but I still feel guilty about that

because it was a really horrible thing to do, you know... (A:113:10) So I think a lot of my breakdown had a lot to do with escaping that.

Guilt over power contradictions

(A:115:1) I had the last year of sixth form and I wasn't made a prefect, right. But I still had the power to give people detention, which every senior did. But I smoked and I drunk, yeah? Which were the things most people were in detention for, yeah? Which is what the policing was about really...

Abused alcohol as way of dealing with issues at school

(A:116:1) I retook my 'A' levels 'cos I was drinking so much that I fucked mine up at that school, I didn't get into the university I wanted, which is good because I went for accountancy then (*laughs*). (A:116:6) I started taking drugs and didn't stop taking drugs because of my confidence problems...

Complex family dynamics contributed to way bullying was experienced, and difficulty in addressing it

Family issues affected way school bullying was experienced, and in turn, made family seem more powerful than they are

(A:141:19) It's not that my family are massive powerful authority people, it's all mixed up with the bullying as well. It makes them more powerful that they really are.

Trying to discuss issues openly with family leads to being labelled as problematic

(A:136:11) Loads of stuff happened in my life and loads of things contributed to it, and some of it's my family. I don't blame them for it, but I have a problem with the fact that when I try and explore what happened to me I'm accused of blaming people... (A:138:1) (*Participant feels that family's position is:*) "That's just me, that's what I'm like, I'm doing *that* again."

Felt that mother lied about her emotions, and this made it difficult to read people emotionally in later life

(A:168:11) being intellectual is very important to me, and that's because I know that I have problems dealing with my emotions, because I felt my mum would lie to me about her emotions. I remember being convinced for years that I couldn't read people's emotions from their faces. I was frightened of their faces. And so I did this autism test online, it involved looking at people's faces and I scored higher than most of the population and getting right... (A:169:1) As it turned out I was very good at reading my mum, but she would always tell me that I was wrong...

A2) Participant experienced a second phase of trauma in young adulthood

During university participant experienced a breakdown

(A:22:2) I was living – it was a friend's house that I was staying cos I'd dropped out of university. I had a breakdown, but not a hearing voices... what would be called a 'nervous breakdown.'

A series of relationship breakdowns were traumatic

Became paranoid when ex-girlfriend slept with close circle of friends

(A:24:12) she split up with me, and a bloke moves in who's dropped out of university. There's a whole load of stuff – he ends up with my partner, but at the time, I had everyone lying to me about it, including my best friends and the people living with me while this was going on. (A:24:15 – A:24:20) *Participant began taking amphetamines, lost a lot of weight, and had to leave university because unable to cope.* (A:24:20) This girl was forced out – the people were living with me were like: “He's going nuts with all this lying to him” – I found out from somebody in the end that she'd been sleeping with all of – left right and centre; but she just told everybody not to tell because it just sent me nuts – because you know people are lying to you...

Suppression of feelings during a second relationship that resulted in pregnancy and abortion deepened problems

(A:33:4) while on my gap, my year break between to try and recover, I meet somebody else and get her pregnant and she has an abortion. I finish with her for... unresolved issues... (A:36:1 – A:36:6) *Participant had a relationship with a girl who became pregnant. When the girl wanted an abortion, participant didn't feel he was able to say that he wanted to keep the child and had to suppress his feelings.* (A:36:6) So I was very much of the “it's a woman's body, it's her choice.” So I went along with it. Retrospectively *again*, dealing with issues – because I denied my feelings – but it turned out the things I was denying was the fact that I wanted to have the kid and I couldn't say anything ‘cos I thought politically I didn't have a right to say anything, but I had a right *to say something*, I didn't have the right to force her (make a) decision, but I still had a right make my *feelings* known. That's all. But I didn't even do that...

Became involved in an inappropriate relationship with female social worker

(A:126:3) in the time I'm there, I get friendly with one of the female social workers. She ended coming down here with me. And so we ended up living together... (A:174:1) I moved out of the shared house because they were all heavy drug takers and drinkers and I couldn't cope because it sent me nuts, I got too off my face. And I was living on my own and here was somebody to talk to, to sort it out. (A:126:5) she trains as an ASW and I find out about getting drugs – I mean, because of Tardive Diskinesia, I don't want to be on Sulpiride, so they put me on Olanzapine. I put on loads of weight, but I'm on it for about 7 years... (A:126:8) so she leaves me anyway after 18 months because I was a pet project and wasn't what she really wanted in a partner.

Trust issues in relationship breakdown mirrored issues of trust and conditional love with mother

(A:170:1) *(IN the same way that participant felt he was good at reading his mother, despite her telling him he was wrong)* so of course I'm back at university, my girlfriend's sleeping around, living in the same room and telling me that she's been a good girl – well, there's nothing wrong with sleeping around, but she was telling me that she's not doing that... (A:171:1) she told everyone to not tell me. And so I knew people were lying to me and these were people that I trusted. And having gone to a place where I felt shit, I suddenly felt good about myself, but all these people were lying to me. So really fucked things up for me.

Suppression of feelings about parents' divorce mirrored relationship issues and compounded breakdown

(A:24:1) *Participant's parents divorced at the same as when he was experiencing breakdowns in his relationships with women.* (A:37:1) I was not aware at all. I was just numbing everything with drugs most of the time, so I just (said)... "Oh, I just don't care." Same as I did with my parents' divorce, which is why I had a breakdown.

Drug use compounded paranoia

Drug use triggered a tipping point where things noticeably deteriorated

(A:24:1) *Participant was drinking excessively at start of university. Parents divorced shortly after break-up of first relationship which ended in feelings of paranoia.*

Participant was using drugs at time. (A:24:7) I was taking a lot of acid and I had my 20th birthday and we watched *Eraserhead*, followed by *Texas Chainsaw Massacre*. And I don't remember any of it apart from being intensely paranoid. And getting through an eighth of marijuana, which I was 'supplying' at the time – let's put it that way. And... that's a significant moment – I mean there's a whole lot of breaking down from there, but that's when things really started going pear-shaped.

After period of abstinence, started taking drugs again

(A:25:3) my friend came round and I started smoking again, smoking dope and we were doing what's known as bucket bombs...

Dropped out of college a second time after becoming paranoid due to drug use

(A:39:2) I get back to university I meet somebody else and get into taking vast amounts of speed 'cos it helped with my confidence, but after a while I got paranoid. So then I dropped out of university – that university – finally in 92/92 I think. And moved to London with some friends, and my sister. And in London, I started hearing voices...

If breakdown had been addressed, may have recovered before becoming more unwell

(A:30:1) I have only really realised it's a breakdown retrospectively... (A:32:1) Compared to what happened to me later, it wasn't major (*laughs*) (A:32:2) I could probably have recovered from it quite well if I hadn't gone back to university and...

A3) Began hearing voices when breakdown was not addressed

On-going drug use triggered experience of voices

First heard voices during use of cannabis

(A:21:2) I was 20 when I first heard a voice, which was – and this is why it was considered to be perhaps drug-induced. I was doing what was called a bucket bomb with a fiend in a small mining village outside K**** University, called S*****...

(A:26:1) I said to my mate, "Oh I'm going to stop taking drugs" and I heard this massive voice go: "And about bloody time too!" (A:28:1) Then I didn't hear another one until I moved to London...

Amphetamine use triggered voices, which stopped with cessation of drugs

(A:50:1) They'd stopped completely in the first year that I was in N***** and then for the last 6 months it was the summer, and I started going to free parties and started

taking amphetamines and they came back. And I do know the amphetamines definitely did make a difference...

Prolonged use of amphetamines led to permanent experience of voices

(A:40:1) I had a moment. So I took amphetamines and started hearing voices permanently – persecutory ones and all kinds of things... (A:44:1) I was smoking dope and drinking. But then I started taking speed and getting really paranoid. Taking magic mushrooms as well... (A50:5) I went down to visit my gran, and I calmed down and they went away. And then I went back. And then I go to another party and... I have some amphetamines and my voices came back immediately. And they never went away – from that day... (A:55:1) they were intense, they wouldn't leave, they kept on going on and on at me until I fell asleep out of exhaustion, and then I'd wake up and (*snaps fingers*) – I'd have that moment when I'd wake up (thinking) "they're gone"! and then "Ourggg! They're there."

Interest in social theory merged into paranoia and was expressed through voices

(A:39:6) I was involved with a certain free-party group that had reached the number 23 from Robert Anton Wilson's Illuminati Trilogy, I was into 23, I had Alistair Crowley's Magic and was reading about Chronozon and all that sort of stuff and got really paranoid and I was walking down West End Lane, thinking about this stuff, thinking about the Eschaton, the Eschaton, which supposed to be the eschatological ending for the change – for things to move on: Age of Aquarius, or communism. They're all eschatological, or eschatons. and a bloke shouts out: "It's already happened!" but I was thinking this to myself, I wasn't talking about it, I was just walking down the street. No in fact, I think it was "The eschaton has already happened!" So whoooo! I'd heard voices, I'd get stoned with my friends, I'd have, I couldn't leave the house, I got agoraphobic, but I'd hear people shouting "Come out, come out!" So I left London (*laughs*)...

Participant began hearing voices in music

Participant began hearing voices in patterns of music

(A:58:2) A lot of my struggles were (about) trying to hear what they were actually saying. So a lot of it was very muffled and very unclear. Yeah? So I would try – I would hear it in the music – I couldn't listen to music because – not even just the words, or the people singing, but in the bass lines and the drums, I would be able to interpret words...

Began to use music as a way of trying to control the voices

(A:59:1) I had a bass. And I would play the bass and I would relax and I would let the voices speak. And I would hear them in the bass and then I would talk back by putting voices *into* the bass (*laughs*) I know that sounds crazy. But – well it was crazy...

(A:60:1) So I'll have a conversation... (A:61:1) Whatever's on my mind, except-usually obsessions.

Participant reasoned that the voices were telepathic communications

(A:66:1) so basically, I started hearing- I was listening to a lot of... not just dub and reggae, but *industrial* dub and reggae - On-U Sound Systems and stuff like that. I got into a lot of stuff about (*sighs*) secrets and stuff like that, telepathy and stuff like that. (A:57:1-A:57:10) *Participant went to a festival and became paranoid because his voices were telling him that people were able to read his mind.* (A:57:3) And I was

trying to escape the voices and the people and I thought it was telepathic communication, I'd found a – you know – sort of new way of communicating. I though – well I couldn't cope with it... (A:57:10) my voices were telling me "They're following you, you're so high, they think you're on acid and they find what you're thinking very entertaining."

The voices were persecutory

Repetitive patterns in music gave rise to voices that expressed paranoid ideas about rape and incest, which led to further persecutory voices

(A:66:4) I started hearing this word, which was "racist system." (A:67:1) But it transferred into "rape your sister" and then what happened was that my voices were like, "We didn't know you did that"... And I was like (*cautious laugh*) "I didn't", but I was like, "No! I didn't", but then they started saying, 'But why are you saying that?' So then I started getting really persecuting ones, interrogating about me and all this sort of stuff. I haven't heard that for years, but at the time I was sectioned I was hearing it – I wasn't sectioned but I went in voluntarily...

Persecutory feelings projected into external objects

(A:81:1) It was too powerful – I was catatonic sometimes. I'd be so paranoid that... (A:81:5) The dog would be scratching (*mimes dog scratching*) "yeah, yeah, yeah (*whisper*), you're fucked. You're fucked."...

Persecutory voices provoked a violent attack

(A:127:3 – A:127:8) Visiting a nightclub with a tense atmosphere, participant became paranoid and started hearing a persecutory voice. After feeling inspired by recovery movement, misinterpreted the advice to try and understand the content of psychosis, and instead, (A:127:8) I though it said "Go with, treat your belief as real" yeah? So I though, "Ok, it's telepathy, people are really talking to me like this and giving me this abuse and I'll treat it as real." I'd drink 9 pints, get really paranoid and I'd think this bloke's calling me a rapist, so I just take a flying leap and drop kick him... (A:129:1) I had him on the floor and I'm about to punch him in the face and I look at him and he's looking at me, like shitting himself (*laughs*) and I realise "There's no way he done that."

Underlying stress provoked voices

Presence of voices were often linked to increased stress

(A:41:1 – A:42:1) *Participant felt that increased levels of anxiety and stress were often related to presence of voices.*

Stress of living in London made voices worse

(A:47:1) I was generally stressed all the time. I was living in London on income support and I couldn't afford to live... (A:48:1) And I'm not a big city person – I'm one of these people who says, "I like visiting London, there's a lot of interesting stuff going on, but I can't live there. Uh... N***** is a smaller city and I found it easier..."

Caffeine makes participant anxious, which increases voices

(A:51:1) I still hear voices. In fact, I've given up coffee, because it makes me too anxious. It makes my voices worse... (A:52:1) As I found out 20 years later (*laughs*)...

A4) Participant has mixed feelings about the schizophrenia diagnosis

Participant dislikes the term schizophrenia

(A:17:1) I was originally – they originally wanted to diagnose me with amphetamine psychosis. But it didn't go away. It became schizophrenia... (A:9:1) I don't like the term schizophrenia. (A:10:1) I don't really care (*laughs*). I just find when I get better, they change my diagnosis.

Participant's diagnosis was changed without his consultation

(A:3:1 – A:3:4) *Participant realised that his diagnosis had been changed by his psychiatrist from schizophrenia to schizophreniform disorder without notifying him.* (A:11:1) I just accept that that's what the *medical* psychiatric establishment – profession, has found itself in. Diagnosis and pill – in a larger extent.

The schizophrenia label can be expedient at times

(A:129:4) (*After attacking innocent bystander because of persecutory voices*) the police intervene, but let me go when I say I'm schizophrenic (*laughs*) and the bloke says he doesn't want to do anything about it.

Biological interpretations of 'schizophrenia' helped participant, his family, and his doctors, to not think about complex family issues

(A:134:2) Very early on, I was very into the biomedical model as an explanation for my illness. Chemicals and all that stuff... (A:135:1) Because I understood myself, as there's something wrong with me, and that, I was told again and again that, you I can't blame anyone else for what happened to me, so then I thought it must be something, it must be genetic or... (A:136:1) Social workers, CPN, doctors, my family. My family were *really* into the genetic thing as an explanation. Because the thing about genetics is it's a chance thing that you carry with you, you know. Nobody's to blame for having... (A:136:9) schizophrenia, as they found out, a lot of it is to do with the environment, and you're blaming the genes, you're taking the responsibility – the responsibility of your contribution – not that you're to blame, nobody's to blame.

Diagnosis gets rid of the therapeutic relationship

(A:14:1) (Diagnosis) gets rid of the therapeutic relationship... (A:15:1) it's part of the idea that the psychiatrist has to have a medical degree, whereas a psychologist doesn't. Or a social worker, or a CPN. (Or) Therapist.

A5) After receiving schizophrenia diagnosis began to drift

Parents were in new relationships and were not able to care for participant after diagnosis

(A:124:1) I get diagnosed in B**** Hospital, spent five months in there. This is nineteen ninety, I guess 94 I think – might have been 93, 94, 95, can't remember... (A:124:5) it was over Christmas. And so... I... My mum was having problems with her part- her step fa- *my* step father – her husband, who was 15 years her senior. So I couldn't live with them. My dad is, was in a relationship with someone 15 years his junior and she wouldn't have me. My grandma was 77 and everybody was telling me she was too old, and so I was put in a half way hostel in S** A***...

Because of association of voices with a town where he had lived, participant decided not to take up a new university course

(A:125:12) I managed to get myself on a sociology degree course in N***** – I hadn't started. And even also managed – I managed to get myself – so when I was hearing these voices and when I was half the time catatonic, I managed to get myself a taxi licence – God knows how... (A:125:15 – A:125:26) *Participant decided however, not to take up the place because he feared that his voices would get worse of he were to return to N*****.*

A6) Psychiatric medication was helpful, but had serious side effects

Medication helped reduce 'psychotic symptoms'

Medication helped reduce persecutory voices and ions

(A:125:4) the medication really helped me. (A:146:1) they (*voices*) weren't as persecutory (after taking medication)... (A:147:1) Also, one thing they did take away was that I used to have delusions. For example, things were significant. So if I was thinking something, couldn't light my lighter straight away, it meant that what I was thinking was actually wrong. I did test that by asking, something like, 2 plus 2 equals 4 and it flicked twice and I thought "Well that's bollocks then" (*laughs*).

After taking medication, no longer heard voices during one to one conversation

(A:121:1) One to one, like now – don't hear voices, never have... (A:122:1) Before I was put on medication I did. But now, I very rarely hear any one to one hear voices. Unless actually, funnily enough when I'm in an argument, which I only do with my wife...

Medication had traumatic side effects and participant was put on a series of different medications

(A:125:4) I was on Haloperidol first, but I seized up and my sister saved my life, because I was (*mimes head thrown back, choking*), because it pulled my neck muscles back and I'd gone and asked for help to get the anti- Procyclidine, or whatever it is injection that hadn't come for me... (A:125:11) So I get put on Sulpiride and I go and- this half way hostel... (A:142:1) (Later, medication was changed to) Olanzapine. And Risperidone. I came off that because it was giving me weight problems and the psychiatrist decided that I shouldn't be on it, it was dangerous. So he put me on Risperidone. Well he didn't, he put me on Quetiapine first and I had a breakdown again, so then he put me on Risperidone and I improved loads...

Medication facilitated management of voices, but not recovery

(A:144:1) first of all, they took about that much off – they took a foot off out of five foot. But it was manageable, I could live. But it was manageable, that's what it was – management. Not therapy, or recovery, or anything...

A7) Initial contact with psychotherapy was unhelpful

Had short term counselling with cpn, which was not helpful

After 7 sessions with a CPN told that CBT was all that was offered by NHS if more therapy was wanted

(A:155:16) I realised I need outside help, so I went to my GP to ask to see to get some counselling. And they put in me in touch with the CPN and the CPN gave me 7 sessions (*of unspecified* therapy) and then said “The NHS has nothing to offer you.”...

(A:156:1) Because I didn’t want CBT and there’s nothing else in S****... (A:156:2) there weren’t at that moment any long-term psychotherapists, except for people who are *really* fucked, and I wasn’t. I was in recovery.

One persecutory voice was a representation of CPN who was experienced as a dismissive female version of his father

(A:141:17) I have another voice, which is called ‘the bitch’ which my CPN, the CPN who did the 7 weeks stuff (*sessions*, thought) was a female version of my father, which was very, you know, “this is rubbish. You can’t think this, this is ridiculous.”

Didn’t want CBT because felt that it made a judgement about normal and pathological thought, and wanted to explore experiences instead

(A:160:1) I’d looked into the way it works and as far as I was concerned a lot of it is to do with the way we think – changing the thought patterns. But there’s a certain sense where, because that relies on the idea that certain thought patterns are pathological, it’s kind of telling you that you’re thinking wrong, whereas I think that the way I think is perfectly normal considering my experiences, so I’d like to explore my experiences thank you very much... (A:161:7 – A:162:1) *Participant feels that being in CBT therapy would feel like a replication of the pressure to fit into the family and school structures that have been problematic in the past.* (A:161:1) I don’t want somebody else telling me how to rearrange my thought patterns. I know I have done some minor CBT with people and they say “Oh this works. This coping strategy works, that coping strategy works, why don’t you try that, why don’t you try that”, but if I’m going to do that I’d rather go to a Hearing Voices group and do it through peer support rather than through a clinical person. If I’m going to have someone in a therapeutic position, I’d rather have them doing the exploring my experiences, rather than telling me...

A8) The first stage of recovery began when participant entered long-term counselling

Entered counselling to deal with life issues rather than ‘symptoms’ of ‘schizophrenia’

(A:129:7) I walk into the counsellor(’s room), and I say to him, “Listen” – ‘cos he said to me “I’ve never dealt with schizophrenics.” So I said, “That’s alright, I don’t want you to deal with my voices, I don’t want to deal with my schizophrenia, I want to talk about my life – my life is a mess, and if I can sort my life out and my relationships and all that stuff, then I can sort myself out”, which is what I did with him for seven years... (A:130:2) I would talk about the voices sometimes, but only if it was related to the problems and relationships that I was having people in my life.

(A:173:1) My counsellor really helped me in those years. Kept me on the level. You know not as far as mental health recovery was concerned, but in sorting my life out.

During counselling, wasn't able to speak about being bullied because it triggered persecutory voices

(A:118:2 – A:118:5) *Participant's counsellor worked for an organisation that counselled clients who had been traumatised by boarding school and were suffered mental health problems as a result.* (A:118:5) he would have been the perfect counsellor to talk to about it, and I couldn't talk to him about it. To his credit, he never – well he asked me occasionally – but he never pushed me on it (*being bullied*)... (A:119:1) It was too difficult. I was- and also, my voices were a lot more intense, so every time I talked about something that... hard, they'd come down and have a go at me. I was too paranoid about my voices. My voices were too powerful for me to be able to do that... (A:120:1) when I was out on the street and they would start picking on things that happened to me or (I had) talked about. And 'cos I had a thing of telepathy, I would think the busy street could hear it, all my internal- I was naked to the world...

A9) Second stage of recovery began when participant encountered the recovery/survivor's movement

Recovery movement encouraged participant to engage with the world, which helped build confidence

(A:131:2) I started a business up, and I went through that, and then I got my MA and I did all that sort of stuff. I started trying to do something with my life. Things that the recovery movement says you should do. Get out in the world and do stuff...

(A:131:8) it meant that I was able to get out and about 'cos I felt productive.

(A:132:1) -It was about building my confidence up as a person, rather than as a label, of a 'schizophrenic'.

Contact with survivor's movement encouraged participant to come off medication and go into therapy

(A:174:4) if I had had access to knowledge about the survivor's movement I would have probably got into therapy quicker and I would have come off medication sooner.

A10) the third stage of recovery began when participant entered long-term psychotherapy

Saw clinical psychologist intermittently, who shared an interest in hearing voices, which was helpful

(A155:21) He took me on – something along the lines of he knew me personally – but he had too much of a workload and he kept on going off sick because he was stressed, but then he took me on intermittently, but then I got a job – he helped me – we were both very interested in hearing voices...

In Lacanian therapy has been able to describe the voices and how they are experienced

(A:79:8) I haven't explored yet why some of the voices I had took the form that they did... but at the moment with the therapist that I'm with at the moment, I'm exploring the fact that they do this, not the content of them yet. Because I've only just got to a place where I can do that.

Explored position of doubting own reality with lacanian therapist

(A:80:1) my therapist suggested to me that's what the rampant superego does, it depicts, it tries to put you down and destroy you and so part of the nature of it trying to destroy you is that you will doubt your own reality. So I was in a fragile place where I was doubting my reality so I didn't have the confidence and strength – from the experiences I've had since then have built me up and the confidence in who I am and what my life has really been like to challenge this.

Lacanian therapy helped to make sense of, and work through, complex family dynamics

Explored how adult experiences related to structure of childhood experiences

(A:24:24) turns out (*issues with trust and lying in relationship and circle of friends*) was bad for me because of my school experiences, and the way – I'm looking into it now with therapy, all these years later – the way my mother treated me. So that really sent me haywire.

Explored how unresolved conflict has been passed down through family in language

(A:139:10) I use language, very much as an automatic reflex because the language was given to me, and I'll realise that I don't mean that. I mean I have massive discussions with my partner about this. She'll say, "Well you just said that" and I'll say "That's what you say in your family and that what I'll use in my family." But actually, I meant *this* and I can retranslate it into a different way which I'll trying to struggle to, you know, understand. And Maude Mannoni said in the language that is used (is) the unresolved conflict that's been passed down from the parents, which I find very interesting from my experience...(A:139:1) I'm exploring that with my therapist now, the Lacanian therapist.

Wife's experience of participant's family made participant re-examine his own experience of his family

(A:153:1) I started getting really, really tired... (A:153:4) But of course we were having problems – me and my wife were having problems... (A:155:1) a lot of my wife's depression was to do with the way my family was acting... (A:140:2) my family fucking treated her like shit. Not intentionally, but just by pushing her out the way and trying to get to my son. And I suddenly saw by proxy, the way I'd been treated... (A:141:1) I was expected to behave. And I started looking into the way I was expected to behave. With my mum it was one of (*sighs*). Ok, I'll give you an example. A little while ago, I stood up to my mum and 'cos she'd come down to visit and my son went was being a bit naughty and she goes "Don't do that, you'll make nanna cry." And I said "Don't ever do that again, he'd not responsible for your feelings." But basically, that explains, my mum would say, "Oh, don't do that, you're making me unhappy. Don't do that you'll make me" – she used the most manipulation. And my dad was a very conditional father, he takes no interest unless it meets some achievement which he merits as... (A:141:13) I'd been on this medication for years, I

was coming off it, and I suddenly realised they'd said to me, "Oh, on medication, you're just like your old self." I was passive on the medication and that's what they wanted – to fit in. They'd always expected me to fit in.

Explored the confusion arising from the appearance of unconditional love from mother, which was given with conditions that participant could not meet

(A:165:6) my father gave me conditional love, I had to behave and achieve certain goals to get his love, but my mum gave me unconditional love. But, it gets a bit fucked up in the fact that she gave the unconditional love to a very good boy. When I started having difficulties, I wasn't a good boy. So she could manipulate me by telling me that I was making her upset because I wasn't the good boy that she gave unconditional love to... (A:166:1) So she gave the conditional love to somebody else. She thought it was me, but I never thought it was me.

Able to openly explore issues of power with Lacanian therapist

(A:164:2) I've only just started seeing her and I'm enjoying it, but there are certain worries that I might be another pet project, like that woman (social worker) I was in a romantic relationship with. She (current psychotherapist) said the same thing to me that my supervisor said to me which was "I'm going to learn a lot from you", and I had a real problem with that which I have explored with her, fortunately I was able to bring it up with her because fortunately she is my analyst (*laughs*) and we explored why I had difficulty with that.

Lacanian therapy provided a language for thinking about issues

Understanding experience through the language of psychoanalysis

(A:69:6) looking back, my voices – as my current therapist says are, what does she call it? A... Not runaway superego, but... (A:73:1) Rampant superego! That's what she calls it.

Understanding issues through language of Lacanian analyst

(A:165:4) she describes it (*arguments with wife*) as – in Lacanian terms – my issues with the Other. It puts a burden of expectation on me, which I have had from my family...

Choice in type of therapy is less relevant than the quality of the therapeutic relationship

(A:174:7 – A:174:13) *Participant talks about the dodo effects in psychotherapy, where some have suggested that all modalities of therapy are equally effective.*

(A:174:13) I think if you take that dodo effect and you take people's belief systems, then actually the therapeutic relationship is what counts. And although I see a Lacanian therapist, it's not because Lacanian therapy is better than Carl Rogers, or CBT, but because as you said, CBT, I have issues with it. I don't knock CBT in the sense that I don't think it doesn't work for anyone, I think it works for a lot of people. I think personal transactional analysis works for a lot of people, Carl Rogers – what's his one? – works for a lot of people, and Lacanian works for some people...

(A:174:20) It suits me so I chose that on purpose because it's something I can work with. And that's me taking an active part in my therapy, but ideally I would like to have a peer support environment where I can discuss this. But there isn't, I haven't found one. So in the meantime I'll pay for one.

Recovery is not about cure, it's about living

(A:179:1) Recovery is an interminable process. Recovery is not about cure, it's about living, you know, finding a way of life. And that's why therapy isn't – self-help is a form of therapy, but we don't live in a world where we can be autonomous, so therapists are necessary...

Therapy has an important role in an inter-subjective world

(A:180:1) I'm not an individualist, we're inter-subjective, which is why I think is why I think therapy is important.

A11) The voices have an underlying meaning that needs to be understood

Persecutory voices were related to bad experiences at school

Abusive voices were representative of being bullied at school

(A:70:3) it turns out a lot of it is based on my boarding school experiences, you know, being bullied. And they would find anything they could to have a go at me. (A:71:1) over the years I've had lots of different accusations of different things... (A:72:1) they usually have something to do with the news, so sometimes it's "racist" sometimes it's "Nazi", sometimes – it's stopped being "raped your sister", then it became a "racist", then it became a "paedo"... It's going back to being a "Nazi" again.

The Fact Voice was a metaphor for an annoying 14 year-old boy

(A:87:3) The fact voice, I call the Pissant Twat... (A:88:1) *Pissant Twat*. Annoying little shit, yeah? And it's a 14 year old, but with a, what I call a 60, 70 year old engineer's attitude... (A:89:1) Which is, you know (*sighs*) very empirical. Empirical facts, very Newtonian, no quantum physics... (A:92:1) Yes. But *annoying*. Because he just goes on and on and on about stuff in a way that a 14 year old would be when they're picking on someone... (A:93:1) Yeah, the 14 year olds, yeah. That's when I was being bullied...

Voices seemed to be all-seeing, like Bentham's Panopticon, which is reminiscent of participant's boarding school

(A:103:8) I recognise the Panopticon (*Jeremy Bentham's system of surveillance*) in my voices and... (A:104:1) (In the Panopticon) there's a tower in the middle of a room and you look into cells all around, alright? And the tower's up there and all the cells are back-lit, so that from the tower, you can see into every single cell... (A:106:1) But the point of a Panopticon is that because you're up in the tower, they, *surveyed* can't see the *surveyor*. So you don't actually have to survey all the time, yeah? Because they just have to know that you might be up there, but you dunno when, so that they can behave... (A:107:1) I would try not to actively think about things, just in case I got attacked. (A:108:1) you know, you can't control your thoughts completely, so sometimes I would and I wouldn't be attacked, but then suddenly I would, you know... It was a very panic and fearful state. (A:108:3 – A:108:10) *Participant recalled both school toilets and dormitories had low partitions between toilets and beds, making privacy impossible...* (A:111:5) every cubicle you could see into it. And that was designed to make it easier for people to make sure people were behaving... (A:112:1) So I thought to myself, "Is there a possibility I'm escaping the strict authoritarian regime of the school in my breakdown."

Persecutory voices have foundation in contemporary life events

When issues of trust and truth were involved, voices accused friend of lying to participant

(A:81:9) I remember saying to him (*a friend*), “Listen right, I think everyone hates me”. And he said “Yes, but you know I don’t hate you.” And I said “Yes, but even while I’m standing here facing you, yeah and you’re telling me you don’t hate me and you’re telling me that you know that I know you don’t hate me, my voices are still telling me that you’re lying to me.” (A:83:1) with him, there was a particular thing, in that he was one of the guys I was living with when my *ex-girlfriend* had told everyone not to tell anyone that she was sleeping with (*people that participant knew*).

Persecutory voices express stress associated with pressure to excel at PhD

(A:165:1) when I got my review back from my PhD and it was saying that it was really good I had to go for a walk and ended up having an argument with my wife afterwards because I was freaking out because I couldn’t cope with it. (A:76:2)... my voices were going “Facts, facts, facts!” (*and accusing participant of not basing PhD on facts*) So I find out the facts... (A:79:2) So I’m thinking about, “Oh God I can’t believe- I’ve just found this out the other day and I’m thinking about it again: “Where’s your facts, facts, facts?” So I told the, “Look, *these* are the facts, look it up yourself.” And they go, “Oh! Don’t believe you. Rubbish. Absolute rubbish!” And I said, “So what – I’ve actually shown you that I have the facts to hand and now you dismiss the facts – the actual facts that I have.”

A12) Other factors that have helped with recovery

Relationship with wife has been a supportive learning experience

(A:168:2) she’s been one of the best people to talk to about what’s happened to me. But you know we can’t be each other’s therapist, we’ve got too much shit, we’ll do ourselves damage if we keep doing this to each other.

Philosophy interests have aided recovery

(A:147:6) one of the reasons I do philosophy is I’ve had to rationalise the world I live in because all the repressed shit has overflowed at some point and made my ability to reason in the world... (A:147:10) It was perfectly understandable, what I think now, reaction to what I was going through, of trying to make sense of the world. But to live in the world, you have to make sense of it as much as possible similar to other people... (A:148:1) my PhD now is about how the world is actually about sharing reality and some people have more say about reality than others. Not just economically and philosophically, but psychologically...

Being actively involved in work helped with recovery

(A:152:1) I got myself a job as a taxi driver and actually, my voices get a lot better when I’m concentrating.

A13) Coming off medication was necessary to further recovery

Needed to come off medication to work through feelings

(A:141:21) There's a whole load of stuff that's mixed up with, you know, I've been trying to understand my feelings, which I haven't been able to do because I've been on medication. 'Cos my wife's got her own background, sometimes I have to...

Given 7 sessions with cpn to test whether he was able to come off medication

(A:6:3) he gave me seven sessions because he was permitted to. It was actual therapy instead of the chatting stuff they sometimes do. And then he was like "ok", you know, he accepted that if I saw a psychiatrist- discuss- I knew I was aware enough of my illness, to discuss with a psychiatrist reducing medication, which I then did.

A14) Statutory mental health services do not meet people's needs

The mental health system should be different - service user self help groups should be used more because they are therapeutic

(A:176:1) to be perfectly honest, I think the whole system should be different and they should be – the reason is due to the economic system, people with mental health problems are isolated so they can't get together to create their own – sorry, I'm going to be an anarchist here – an autonomous, spontaneous self-help groups. I'm trying to start one, I'm absolutely exhausted, but I'm trying to start one to help people. They have done – you know, if you read the survivor history, movement, there are groups that have formed up, some are still going. Threshold in B***** is one. It's now become official, but it started up that way. It now offers counselling in a way that's user-orientated, that type of thing.

A more democratic society would be a more mentally well society

(A:176:10) I think therapy is necessary because of the way that society is, but I think.... Ideally in a utopia, people should be able to learn therapeutic skills to help each other... (A:178:1) That's because I'm an effing hippy anarchist (*laughs*). But you know, yeah. That's my ideal, but that world doesn't exist... (A:178:4) I would like to help create a society where people can decide how to lead their lives in a way that they can't decide now - a more democratic society, in a democratic form.

Participant B – individual depiction

Now in his late fifties, (B) has experienced a number of different forms of psychotherapy since he had a psychotic breakdown in the 1970s, aged twenty-four. In hospital (B) began to hear the voice of the devil who urged him to kill himself. (B) was treated with antipsychotic injections, which he found helpful, and continues to take. However, he felt medication did not address any of the underlying issues, and after working for six months as a cleaner following his discharge, he experienced a second breakdown. He was re-admitted to hospital, and once again, medication was the only treatment offered, and underlying issues continued to go unaddressed. After a period of time in hospital, (B) moved into a residential TC where he had his first experience of psychotherapy.

(B) felt his first psychotherapist³⁸ was not interested in him, and finding this unhelpful, asked to work with another psychotherapist. He worked with the next psychotherapist for approximately a year, and valued her authenticity and her interest in him. This felt like a million dollars, because the experience of being liked helped to heal what seemed like a broken brain and a broken heart. In the twelve years following his time in the TC, (B) worked with first one, then another counsellor/support worker at a drop in centre. This helped him deal with day-to-day issues and this structure felt less pressurised than previous psychotherapies he had experienced. (B) has spent the last five years participating in group psychotherapy, which he has found the most helpful way of working through some of the issues he feels underlie his symptoms.

(B) feels schizophrenia was a way of escaping intolerable pressures; a sort of mentally checking out. (B) grew up feeling unable to communicate with his family and felt isolated and lonely. At boarding school, he felt a pressure to conform to his parent's vision of a middle class life, and while initially a popular, sporty boy, he felt this was only a persona he inhabited to mask deeper problems. When a gay rumour about him went around the school, he felt deeply affected and fearful. After leaving school, (B) trained as a chartered surveyor, but felt unable to fit in and cope with work pressures. He became increasingly fearful, and this fear culminated in waking from a dream in which a pair of green eyes were staring straight into his head. He was hospitalised soon after this, and began hearing voices. Although (B) rarely hears voices now, he still fears them, and feels they express deeper issues with sexuality, in particular an interrogating 'devil voice'. He also feels there may be a paranormal dimension to voices, and believes people who hear voices may have spiritual abilities.

(B) believes good relationships dictate the usefulness of all forms of treatment, including where the treatment only involves medication being prescribed and monitored by a psychiatrist. When he feels he is a nuisance, or a frustration because he is not progressing in the way a clinician would like, or there is unspoken tensions, treatment is not helpful to him. By contrast, where there is a feeling of interest and a sense of care for him, the relationship can be healing and helpful. (B) lives alone in his own flat, and continues to attend a therapy group, when he feels well enough.

³⁸ (B) was not able to confirm the modality of the psychotherapists he had worked with.

B1) Grew up feeling isolated from other people

Wasn't able to communicate with family

Felt parents had good feelings toward him but had nothing to say to each other

(B:34:2-5) *Participant felt that both parents had 'good feelings' toward him, but*

(B:34:5) It's just one of those things, we had nothing to say to each other. And you can do that with a friend in life, you can have relationships with people, you can like people but not be able to communicate with them. And this is what happened with my mum and my dad.

Didn't have good relationship with sister or wider family

(B:35:1) the relationship with my sister now is actually quite good - but then, she wasn't interested in me at all. She was 5 years older than I was and I was just a little, I was just a little chap who basically was sort of, she didn't really have much time for really. It was all a bit sad really (B:35:6) I had some aunts and uncles, but I didn't get on with them very well.

Grew up feeling 'deeply inside', sensing problems building up

Growing up a 'deeply inside', lonely and unfulfilled person

(B:38:3) (there was) this theme of growing up on your own, being someone who grew up on their own, being a lonely person who's deeply inside. And having a lot of unfulfilled stuff as well.

Felt unable to talk about problems that were building up

(B:41:1) Things were building up, I'm telling you about things building up at the time. Building up to someone who had a lot of problems, but unable to talk about them. To anybody. And that's my experience with a lot of people with schizophrenia. They're lonely children...

B2) Feelings of confusion and things coming to a head during adolescence/early adulthood

Successful coping persona at school concealed trouble beneath

(B:35:7) it was all masked by the fact that I was actually quite a sociable person at school and I did very well at school. You know I was in teams, the rugby team and Fives at school, and I did very well at school. (B:36:2) But something was going on inside me. Something different from what I was doing. Something, there was something that wasn't quite right. And the funny thing was that I was the only person that could see it. (B:36:6) it all came to a head suddenly, I had a situation whereby I was left to my own devices and I didn't fancy sort of, it all came to a head really...

Realised couldn't cope in the world of work

(B:142:2) I couldn't believe just how pressured it was – the professional life, I couldn't believe it, you know. (B:36:9) I realised I couldn't hack it in business and I was too sensitive for it. (B:37:1) (I was) Frightened. I was going into my shell too much and I didn't believe in it either. There comes a point with business where you've got to believe in it a bit. People listen to what you're saying. I wasn't getting anywhere promotion-wise either, I was being side-lined...

Experienced a widening gap between self and family

Felt pressure to please parents and conform to the 'middle class' package

(B:19:1) if I was brutally honest, I'd say I wanted to please my parents really. The middle class thing, be alright, you know. And that's what it was about really. You'll be alright in life, have the best in life. Wife and 2 kids, the car, holidays, the whole, the whole middle class package. They sent me to a public school - my parents - and they wanted me to have the best in life.

Realised wasn't able to communicate with father

(B:30:2) I'd never really got on with my dad. And I'd come to London in '76 originally, and it suddenly became more obvious that my dad and I didn't have anything to say to each other. I mean, I had friends back in B*****, where I came from at school. And I didn't really notice the fact that my dad, I had a terrible relationship with my dad.

Confusion over sexual identity

Had fears about sexual identity and felt unable to perform sexually

(B:39:1) I suspected I might be gay, but I was prepared to accept anything at that point. 'Cos my, of a relative lack of sexual experience and you know, when I got down to the crunch, you know, of sexuality, I couldn't really do very much. I wasn't, I couldn't perform, there was something that wasn't quite right. And that upset, that unsettled me as well.

Became very frightened when a gay rumour started about him at school

(B:116:1) I had an experience at school which frightened me. (B:116:2) it was a gay rumour I heard at school. And I was a real success story at school, monitor, head of house, and ... in the rugby team and everything. (B:116:5) So I think some of the other boys they got turned on by me. (B:116:10) And a rumour went round that I was gay. It wasn't a serious rumour, but it seemed serious at the time and I was frightened, desperately frightened by it.

Relieved that first sexual experience at 24 years old was straightforward

(B:40:1) I'd had a sexual experience in '77 and I hadn't enjoyed it. That was my first sexual experience. (B:41:1) I was 24. And that threw me as well. (B:42:6) it wasn't S & M or anything like that or, or bisexuality or, underage, or anything like that. It was quite straightforward. And that came as a relief.

B3) Traumatic experience in young adulthood

Moved to Canada to start new life, but was deported

(B:38:1) I went out to Vancouver, thinking there'd be a better experience, but I discovered it's just the same really. And you know, and I was lonely out there as well. (B:12:2) I got a job out there and I had the immigration people ask me 'cos I hadn't got my paperwork sorted out, and they said well leave by the end of the week. And I left by the end of the week, I did what they said.

Returning home, felt isolated and unable to cope

After deportation from Canada, felt a failure and couldn't cope

(B:144:1) it was the first time I'd ever known failure in my life. At the time when I was 25, and I couldn't handle it really.

After deportation, friends had moved on/felt isolated and lonely

(B:12:5) I was a bit shaken when I came back to London, and I was very lonely.

(B:12:6 – B:12:9) *Participant B felt that friends had settled into careers and relationships and no longer had time for him.* (B:12:6) It was a very lonely time for me in London, when all my friends at 25, you must have found this Tom, at 25 they, you know people they settle down, they get girlfriends, settle down to careers and everything and if you're somebody that hasn't done that, you know the phone stops ringing...

When career failed, had no alternatives

(B:20:1) I didn't have anything apart from chartered surveying. That was the problem really. (B:21:2) I'd lost interest in chartered surveying, and that's what frightened me as well. But I didn't have anything to move into. (B:22:1) No Plan B. And that, you know, that was a real problem I had. (B:22:2) And I got desperate, I got desperate so...

B4) When began experiencing 'psychotic symptoms' breakdown seemed irreversible

Felt like an external force had entered head

(B:2:3) at about half past 2 in the morning, this pair of green eyes suddenly flashed into the back of my head. It suddenly looked into my eyes while I was asleep, deep sleep. And I saw this, and what happened was the inside of my head lit up and I started screaming. (B:3:1) And I went into a dream after that. Something collapsed in the front of my head. (B:10:1) something sort of said, "Now I'm coming for you." And something climbed up through my body into my mind. And I had this sort of battle in my mind, it was as if something was trying to take me over or something like that. Some evil force was trying to take me over, and yes it was. Terrifying experience really.

First voice created a sense of euphoria

(B:13:1) I started getting this voice saying I was going to be president of the United States, and some euphoria came over me and I started hearing voices just before Christmas in '77. And I was sort of, I was going that way, I was getting depressed as well. My moods were going up and down and I was getting depressed.

Wasn't able to talk about what he was experiencing with anyone

Parent's couldn't understand breakdown, friends disappeared and participant went into a world of his own

(B:24:1) I couldn't talk to anybody about it. (B:28:8) my parents didn't understand what was going on, they'd seen that I'd come back from Vancouver in '77, and I wasn't very well... (B:34:1) It's the first time in my life I realised my relationship with my dad was hopeless and my mum was quiet you see. (B:34:8) I suddenly realised that my friends were going and I started going into a world of my own.

GP who he had relationship with committed suicide, and found that other GP's were reluctant to work with him

(B:25:1) I went to see my GP about it, and he was having a breakdown himself. In fact he committed suicide towards the end of '78 (B:25:4) in the practice I was told - the GP practice - I was told that there's only one doctor who wants to work with me, 'cos you know I was frightening people. I was getting disturbed. They didn't want to work with me 'cos I was disturbed. (B:5:6) A lot of GPs don't want to talk about mental health issues. (B:6:1) They're alright with things that they can see and touch and help you with, but it's all a bit strange the mind, you know.

Becoming unwell stopped ability to work

(B:11:4) It changed my life of course, my chance of any career was over.

Repeated breakdowns since initial breakdown

(B:126:3) I've had 6 breakdowns, 7 actually. I've had 5 hospitalisations, 2 in the '70s, four in the '80s. I had a breakdown in '04, that was my latest one.

B5) Initial treatment involved hospital and medication only

During breakdown, told that he was not unwell enough for hospital, which was only form of treatment available

(B:44:1) I was talking normally, just a bit erratically, but I wasn't seriously ill.

(B:26:1) I saw a psychiatrist down there (*psychiatric hospital*), and you know he sent me home. Things hadn't got to the point where they'd gone out of control. (B:28:1) They want to see psychosis. They want to see somebody completely out of control.

Taken to hospital after exhibiting 'psychotic symptoms'

(B:44:1) As soon as I had that (*experience of green eyes entering head*) and I started screaming, that's when they took me into hospital. 'Cos I had the symptoms, I had a breakdown, I had a sudden breakdown and they took me into the hospital in the night.

Being in hospital made participant realise there was something seriously wrong with him

(B:45:1) I couldn't get to sleep, I had terrible problems. I was in a world I didn't understand, I couldn't understand it at all... And I realised there was something seriously wrong with me.

During hospital experienced persecutory voices urging suicide

(B:45:3) I seemed to have some problem with the devil or something like that. Some kind of, the devil seemed to be after me, you know, talking to me, things like that.

(B:46:1) Wanted me to commit suicide. And had some ideas about how to do it.

Jumping off... Jumping off buildings, things like that. In fact that was the whole thing about it, I had this voice all the time. "You've got to commit suicide, you haven't done anything in your life." And ... and I had to fight it, you know, before - I was very lucky to survive that period really. And they shoved me out after about 3 months, because I got better.

Only treatment in hospital was medication

Was given medication because had been observed talking to himself

(B:48:1) they gave me injections. Modecate and Depixol. (B:49:1) They said I'd been talking in the corridor, talking to myself.

Medication has been helpful

(B:50:1) I was somebody from the start who was good on the injections and they said that that was a good omen as far as my long-term future was concerned, the fact that the injection worked for me. For lots of people they don't work. And they have serious problems later on. (B:64:4) after a few years I was, they tried me on Modecate, Haloperidol, Deconate, and then eventually, Piportil. I've been on Piportil for about, over 20 years I guess.

B6) Symptoms got worse when issues underlying breakdown were not addressed

Participant experienced a second breakdown soon after the first

Unaddressed issues from first breakdown led to a second breakdown, where voices became more intense

(B:51:1) I left hospital in about April, May of '78 and I went to work at the N**** Museum as a cleaner. (B:51:5) then I started going into myself in the autumn of '78, I started going into myself and I had another breakdown... (B:52:1) The voices were getting more intense and the voices were sort of taking me over more.

During second breakdown, hospital was once again only treatment offered

(B:62:1) I was told to work with one particular GP, and she wasn't very good really. And she said, "Go and see a friend for the evening." (B:62:4 – B:62:8) *Participant B went to stay with a friend, but felt friend wasn't interested in talking about his problems* (B:64:1) eventually I think I walked into hospital for that one. And said, "Look I don't feel very well", and they took me in. And then they put me on Depixol, and I've stayed on injections ever since actually... (B:47:1) the first breakdown they have a look at you basically. They probably expect to see you again, but they didn't give me a diagnosis. It was the second time I went in they gave me a diagnosis.

The persecutory voices became more powerful

Participant's paranoid voices felt a hundred times more powerful than him

(B:8:3) my experience of the voices, the paranoid voices, I call them paranoid or schizophrenia voices, at its height it was a hundred times more powerful than I was. So it's a very powerful thing, it's a very, very, very powerful thing.

The Devil Voice was like a real entity that was having a relationship with participant

(B:53:4) It's like the devil had a personality. It was real. (B:54:2) it's like a personality in your mind. So you've got someone sort of, like a real entity that's having a relationship with you.

The Devil Voice had an accusatory, interrogating nature

(B:55:1 - B:58:2) *The Devil Voice was unfamiliar and seemed to come from nowhere.* (B:58:1) (It was) Like a policeman really. A policeman who's trying to... sort of enquire about, thinking you've committed a crime. (B:59:1) a policeman who actually sort of, you know, is questioning you...

The Devil Voice also had a sense humour

(B:53:2) the voice had a sense of humour and could say really horrid things to me and try, and get me to commit suicide. But could be quite funny as well.

B7) The schizophrenia diagnosis has a powerful impact

Felt that the diagnosis was given insensitively

(B:66:1) my parents came into the hospital and there was a doctor sitting behind the desk I remember, and I was there and I was freaked out and the doctor, and my, my parents turned to me, turned to the doctor and said, "What's *wrong* with him?!" And he just turned round and glibly said, "Schizophrenia." That's, that's how I found out that I'd been given this diagnosis. (B:67:1) sort of like it was just a throw away line. There was no sensitivity about it.

Participant feels he has to play a game with psychiatrists in accepting their interpretation of his experience

(B:3:4) I might call it a spiritual experience, but the shrinks call it paranoid schizophrenia. And I take medication for it – Piportil - and have done for a long time, for the whole of the time, 33 years. And I just, as I say I play the game with the doctors and I don't call it schizophrenia, I just, I don't know what to call it, you know. Very sort of strange experience.

Other people perceive the diagnosis in a negative light

People fear that 'schizophrenia' makes you unpredictable and dangerous

(B:5:1) everybody's frightened of it. GPs are frightened of it... (B:7:5) People do strange things and they hear voices and they sort of, it makes them do things. (B:8:2) Like Christopher Clunis knifing somebody on the tube train... (B:8:6) If it comes into your mind and, and takes you over, it can just take you over. And I think that whole side of it just terrifies the life out of people. The fact that you can have this sort of vicious voice and people believe that the devil's talking to them...

Negative perception of the diagnosis had an impact on participant's work

(B:4:3) You've got to be careful who you tell. I remember I went to a Housing Association, I won't tell you which one. I was doing some admin work for them, and they knew I had mental health problems and I said... and she said - I didn't stay very long, she was one of the workers there - and she said, "Well what have you had, tell me." 'Cos they knew I had mental health problems. And I said, "Schizophrenia." And she said, "Well I wouldn't have taken you on if I'd known that." And I learnt something there.

B8) The quality of treatment relationships has important impact

Good treatment relationships are healing, bad treatment relationships don't do anything for you

(B:67:7) If I have a good time with somebody, and I really feel they like me, I know that... And there's a healing quality about them as well, it's not just that, it's not just that they like me, there's a healing, there's healing things happen between the two of you. But if someone doesn't like you, you know, and what will happen with someone

who doesn't like you, they'll be conscious of the fact they don't like you and they'll move out of your orbit as well. They won't stay in your orbit either, they'll move out, or they won't come into your orbit in the first place.

Feeling cared for and liked by psychiatrist was therapeutic

Felt helped by a psychiatrist who was interested in him and seemed to care about him

(B:69:1) (With first long term psychiatrist) we didn't start off too promisingly, but he really helped me in the end. I was lucky to have him. (B:70:1) He was like an uncle figure or a father figure, I could tell him things, he was someone I could talk to, and talk with. I was looking at that point for somebody, I was all wrapped up in myself in this fearful world and I needed someone to really share my feelings with. And he was there for me. You know, I know he was a professional, and he had a caseload to deal with, but I always felt with him that he cared about me. And at that point when I was so desperate about myself, he was there for me.

Feeling a personal connection 'click' with psychiatrist felt good

(B:93:1) we were in this group together and we were walking back to the unit, and he, it suddenly, it started to rain and we started to run together back to the unit and he said, and he pointed up at a tree and he said, "That's a mulberry tree." And I didn't know that was a mulberry tree. (B:93:5) And you know it was fantastic. Something clicked I don't know what it was. Jung talks about things like that. About how you can have, you can be in therapy for a while and nothing's happening and then that psychotherapist can say something and suddenly you click and you can't put your finger on it. You can't put your finger on what happened, but something happened, you suddenly felt connected to each other.

Feels liked by second long-term psychiatrist and experiences this as healing

(B:69:7) for the last seven years I've seen a psychiatrist up at S****, called H***** and I feel she gets on with me, she likes me as well. And she's helping me, she's helped me quite a lot and I always felt that she's been on my side. And she helps me and I feel there's something healing about all that.

Bad psychiatric treatment relationships did not feel therapeutic

After discharge from hospital, a lack of consistent treatment relationships didn't feel good

(B:71:4) when I first went into mental health, you know I didn't really have a very good time. I'd been moved from doctor to doctor and it wasn't very good.

Experiencing psychiatrists' disinterest, or sense of disappointment to be working with participant, felt bad

(B:71:1) I have had bad psychiatrists - I'm not saying *bad* psychiatrists, 'cos maybe they get on with other people, but they didn't get on with me. (B:77:2) you don't feel they're on your side, that's the problem. You don't feel they're working for you. They sort of look at you and they're, when they first meet you, they're disappointed when they meet you. They're disappointed, they make remarks about you. One psychiatrist while I was up at S****, he said I should take up knitting. I realised when he said that that things weren't very good. (B:78:1) he wasn't interested in me, he was going through the motions. And he wasn't going to help me either.

Being given the message that he was a hopeless case didn't feel optimistic
(B:92:5) we weren't getting on too well and he'd said something like, in fact he'd said something in the first year that I knew him, down at S****, he said, "We're waiting on medical science to help you" he said. Which didn't sound very optimistic really about the way things were.

If you're not making progress, or relationship with psychiatrist is bad, they try to get rid of you

(B:71:7) I know it's a hell of a cruel situation, but if you're not making progress with these doctors they don't like working with you, they don't wanna work with you, they sideline you, move you somewhere else. (B:68:1) if you don't get on with a shrink, he or she will move you, you'll move somehow, whether it's you moving or them moving you, or, you won't see them, they'll get rid of you.

B9) Treatment in residential therapeutic community had mixed results

In residential therapeutic community there were groups and one to one therapy with trainee therapists

(B:81:1) After being in hospital, I went straight from hospital, second time, to R***** (*a residential therapeutic community*). (B:82:1) A therapeutic community. For helping people, a group of mental health people together, helping each other really. And making friends and being, helping, and being... and there were some trainee therapists who the R***** employed, who you could see, or you saw, and they gave you one to one therapy. There was also some group work as well, they helped you in groups.

In therapeutic community couldn't get out of bed because of devil voice

(B:81:5) I was so ill that I couldn't get out of bed actually at the R*****, I just couldn't get out of bed during the day. (B:83:1) Well the devil (was coming) after me and the devil talking to me and things like that. I had this thing where I got out of bed, they had this work group in the morning for an hour and then a group, I just about got out of bed for that. But I had this situation where I couldn't get out of, I went back to bed for the day and then in the night I couldn't get off to sleep. I had this voice talking to me all the time.

Suicidal thoughts were a way of controlling the voice

(B:84:1) I had a bottle of pills by my bed, it was a bottle of something, I can't remember, and I thought if this voice gets any worse and I lose control any more, I'm going to take that bottle of pills and end it all. And people did take bottles of pills in that hostel, and did end it all, jumped out of windows...

B10) Where therapy has been unhelpful

Feeling that trainee therapist #1 was not interested and was not empathetic

(B:84:7) the first one I had was wasn't very suitable and I said I wanted to stop seeing him. (B:85:1) I didn't feel he was interested in me. You know, he didn't have... I was so ill and he wasn't asking me the right questions. He didn't seem to have empathy with me.

Felt that if talked about sex with trainee therapist #1 would have placement at therapeutic community terminated

(B:86:1) I wanted to go into things like, you know, my career and, and also they had a rule in the hostel - no sex in the hostel. So, although I was trying to have sex with girls in the hostel, at various times, I couldn't talk to, I didn't feel I wanted to talk about it to the therapist, because I felt I might be thrown out of the hostel for trying to have sex.

Felt his difficulties with communication were too much of a challenge for trainee therapist #1

(B:87:2) I wasn't very easy to talk to. So there was that whole thing about you know, maybe he needed somebody – 'cos he was training as a psychotherapist - maybe he needed someone a bit more open-minded- not open-minded, open about *themselves* and more talkative, to sort of, you know to help them. I met the wrong person really that was the thing. And then he left to go somewhere else.

Psychiatrist advised that one to one therapy would be too much for participant

(B:110:1) I was advised by my doctor, Dr Br****, to avoid one to one psychotherapy, 'cos he said that it would be too much pressure on me. (B:110:4) I haven't actually done, you know, psychotherapy as such, not in a deep way, when I was coming out of schizophrenia. So the best I've done is this 5 years with Pa****. But that's the best I've done. And, and also I've had therapy, kinds of therapy at a um, at a day centre. Called the Pe**** Centre which has closed down now.

One to one therapy felt too much in hindsight

(B:137:1) I think one to one (*therapy*) was too much actually, looking back.

B11) Where therapy has been helpful

Having a say in choice of therapist

Participant worked with a second trainee therapist at the residential therapeutic community. (B:84:5) I did have one to one therapy with a trainee therapist, a very good one actually called L** and she was very nice... (B:84:8) I saw her for about nine months, or a year. (B:88:1) I was talking about leaving the hostel, and then somebody asked me, he said, "Who do you want to work with?" And I said L**, this woman L**, and they said, "Well you can work with her, she wants to work with you." And it worked very well.

Participant felt that trainee therapist #2 didn't want to control or be clever

(B:96:7) she didn't want to control anybody, she didn't want to be clever with anybody, she didn't want to be angry with anyone or vicious with anyone, you didn't feel an undercurrent of something nasty going on when they look at you. You just felt she wanted to help you and she liked you.

Being sensitive to participant's needs helped trust to develop in therapy

(B:91:2) she (*Therapist #2*) put me at my ease straightaway, when she first met me. She said "I've just come in just to ask you a few questions." And she asked me a few questions about myself and things and she said, "That's fine, that's fine, absolutely fine." And I said, "Is there a problem?" She said, "No, there's absolutely no

problem.” (B:92:2) She could see I was very nervous about the whole thing ‘cos I’d had such a bad experience with the first person.

Experiencing being liked by trainee therapist #2 compensated for past bad experiences and made participant feel good about himself

(B:88:8) I felt I was being treated very well and she wanted to help me as well. Not just in the hostel, but outside the hostel. (B:95:1) She just took me at my own pace. I was very ill, but she was interested, she liked me... (B:97:1) It was worth a million dollars. You know, somebody likes you, you just, because you’ve had so many bad experiences, because your brain was broken and your heart was broken and somebody liked you, for God’s sake. And you weren’t even being yourself really ‘cos you’re so wrapped up in yourself and all mixed up, but someone actually liked you, you know, they cared about you, it’s such a wonderful experience.

Trainee therapist #2’s interest made participant feel worthwhile, safe and less frightened.

(B:98:1 - B:100:1) *Trainee therapist’s interest made participant feel worthwhile, safe and less frightened.* (B:136:1) It told me that somehow that therapy would be, there was something in therapy for me. I wasn’t somebody who was a no-hoper with therapy - or it wasn’t my kind of thing. Eventually, I always felt that somehow, there was something in therapy that was, that was ok for me. Even though my doctor had said that one to one was too much for me really. So...

Feeling a lack of pressure in therapy is helpful

Less structured therapy over 12 years at a drop in centre was helpful because it was less intense

(B:137:3) the therapy I had down at the P***** Centre was ongoing sort of - it wasn’t psychotherapy as such, it was more sort of helping you along day to day, to keep you going. (B:138:1) it wasn’t in-depth psychotherapy, where you let your mind go and talk around things and everything. (B:139:1) there are issues around my schooling and I told them about the gay rumour and I’d tell him about a lot of other things as well. But it wasn’t intense or anything like that, or regular weekly sessions or anything like that. (B:139:6) there wasn’t the pressure involved of psychotherapy, as such. Weekly sessions and things like that. I could just pop in to have a chat, say what was on my mind, and he helped me like that, he was very good like that, a very nice person.

Things bubble up in current therapy group, but there is no pressure to address them immediately

(B:115:1) you talk about what you’ve done in the week, particularly what you’ve done in the week. And I talked about my, my experiences as... One of the things is about the group therapy, things bubble up inside you, or bubble up in the group, and this can bubble up and they can go away for a while and bubble up again. And they can, you can work with that, with members of the group.

Being able to attend group therapy when feeling well enough is important

(B:140:4) I’ve been going there regularly. I don’t go every week, because sometimes I don’t feel well enough to go there, sometimes I’m not well enough...

Group therapy has been helpful in distinguishing paranoia from ‘what’s real’

(B:119:3) with paranoia - you don’t know what is actually paranoia and what is real. You get caught up in this world where, where you know it’s all, everything, well you don’t know what’s real actually and what’s imaginary. But a psychotherapeutic group helps you with that, what’s real. What’s real, what’s really going on and what’s imaginary, you know.

Being able to go deeper into painful issues has been helpful

Group setting of current therapy has enabled participant to deeper into feared issues about sexual identity

(B:113:4) the deepest I’ve gone into myself, is this 5 years at P***** in the group therapy. (B:116:11) I could talk about this gay rumour with the group you know. (B:116:16) So this is something that was important to me. (B:116:20) And I’ve sorted it out really as much as I can. (B:117:6) talking it through with the group and then meeting the old schoolfriends, a lot of that whole situation, 40 years later, has actually come out of my system now.

Therapy has enabled going deeper into the cause of his ‘schizophrenia’, which participant feels were problems in family, and expectations of school and career
(B140:1 – B:140:7) *Participant feels that getting better and deeper into issues, he has been able to go deeper into the cause of his breakdown, which he feels was:*

(B:141:1) The family really. The military public school, the military chartered surveying. I went from a military public school from the frying pan to the fire, with the professional life. You know, the chartered surveying... (B141:8) although they put a lot of responsibility on me at school and in the profession, there’s something in me that wanted to get clear of all that, and just become maybe slightly irresponsible or something, I just want to be myself you know.

Becoming weller enabled going deeper into things and get more out of therapy
(B:40:1) the weller I’ve been, the deeper I’ve been able to go into psychotherapy. And get out of it. (B:140:5) as I got better, I’ve began to go deeper into things. As I’ve come out of schizophrenia, so I go deeper into the whole thing. The whole thing behind it and everything.

B12) The ‘symptoms’ of ‘schizophrenia’ express deeper problems that are rooted in experience

The voices expressed bad experiences

Persecutory voices expressed and amplified fears about sexuality

(B:116:11) the trouble with schizophrenia and a rumour like that (gay rumour a school) or a problem like that, it all gets out of control, it becomes magnified. You know, with schizophrenia, ‘cos you’ve got voices and you’ve got, you’ve got something for the bad voices to latch onto about you. You’re gay, you’re this that and the other. (B:117:1) But what it did at school was, it left a scar on me, it frightened me and it left a scar on me and it’s been, it’s a scar that’s been with me for 40 years... (B:117:5) it’s a very sensitive time, 16, 17, a very desperately sensitive time. And it frightened me.

The Devil Voice interrogated participant about gay rumour at school and felt like being attacked from within

(B:117:1 – B:117:7) *Gay rumour at school triggered voices later that interrogated participant.* (B:118:1) the voices were like a policeman who, were talking to you about committing a crime, and things like that, in that type of tone, you know, slightly friendly, but also quite inquisitive. In quite a cruel way. (B:119:1) and it upsets you. And you lose confidence due to it, you lose that confidence that you know, you're being attacked from within.

Psychotic breakdown was an escape from failure and pain

Experienced breakdown when confronted with inability to deal with 'bad things' and the realities of work

(B:144:2) I was always brought up not to know about bad things, and not to know about failure, and not to know about pain. I was shielded from that. And eventually I had to face it really. And I couldn't handle it. And my mind, my mind went off somewhere for 20, 30 years really. Into a world of my own really.

Breakdown was an escape from pressure to maintain a version of himself that didn't feel true

(B:142:1 – B:142:5) *Participant felt that the pressure of public school was perpetuated in pressure of working as a chartered surveyor.* (B:142:5) I went on and I qualified, but it wasn't me at all and in the end it was just too much, I couldn't play the game anymore. (B:142:8) In the end I was like - mentally - I was like that, that Sunshine Desserts and the guy who left his clothes on the beach and ran into the sea. (B:143:3) That was the schizophrenia. Mentally going off into, running off onto the, into the, the water.

Difficulties with relationships and establishing identity separate from parent's wishes expressed itself later in work and sexual problems

(B:38:2 – B:38:5) *Participant felt that growing up a lonely, insular person was associated with having unfulfilled desires, encompassing issues with sex and the wish to have a life of his own/that was separate from his parents' wishes for him.* Participant felt these issues came out (B:38:6) in work, but it comes out in sexual problems as well.

B13) voices have meaning, but may also be paranormal

Participant understands the content of the voices but not sure where they really come from/might be god of the devil

(B:120:1) the spiritual people they believe that it's a product of the imagination - it's the imagination going wrong. I don't know, I wouldn't like to say. The psychotherapists believe it's all part of the mind really. I mean you know, I mean I don't know, I wouldn't like to, maybe I've got a slight thing there is a bit, something in it that it might be the devil or it might be God or it might be the devil. And you know, it might be something like that. But I wouldn't like to say really, at this stage.

With the illness comes certain spiritual abilities

(B:126:5) I've got certain spiritual abilities that go with it. Being spiritually aware, but I've got... (B:127:1) nothing special really, nothing special. (B:128:1) I'm not a hopeless case you know, I'm not a hopeless case...

B14) Non-clinical therapeutic factors

Exploring sex and sexual issues was healing

Couldn't talk about core issue of sex during psychotherapy sessions, but began talking about this with friends in later years

(B:101:2) I didn't want to talk about sex (in therapy) 'cos it was such a problem area for me. Sex came in later when I got involved with my friends really, I started talking about sex, I got to know people through therapy you know, and I could talk about sex then. And experience sex with women as well, and then things started to ease out you know.

Sexual relationship was therapeutic

(B:102:1) I met her in '96, was it, I knew her for six years. And I was freaked out, I was ill, I wasn't capable of a relationship with a woman really. And she had this thing where you know, basically whenever I wanted sex she was up for it. And the sex was very good. (B:104:1) It was just such a fantastic relationship, and it was what I was looking for really.

B15) Feels more well now than after initial breakdown

The voices have become less threatening, more benign

Felt something leave brain and then voices stopped being cruel

(B:122:1) I had an experience in the night actually, I talk about this guy leering into my eyes, and seeing green eyes, and I had an experience, I felt something move in the back of my head and then something moved forward and then sort of a light went on and then something came out of my brain, and after that the voice stopped being cruel... (B:126:2) after that the angry, cruel voice left me and this friendly voice started returning.

Currently hears voices only while reflecting, like thoughts

(B:122:5) I hear voices now actually. (B:123:1) not as we're talking, but when I'm reflecting I hear a voice. But it's coming from my mind, you know. (B:124:1) Like a thought...

Last breakdown was response to flat being broken into, but did not require hospitalisation

(B:148:1 – B:148:5) *Participant woke in the night to find an intruder in his flat, who he managed to eject.* (B:148:5) But I think it was just too much for me, I couldn't believe it. I couldn't get it off my mind and I haven't got a strong mind anyway, and it was just too much for me. I had a breakdown after that. (B:150:1) I got depressed, mainly I got depressed. But the voices came back as well. Not the angry ones, but it all became, I just couldn't handle it, it was too much.

Looking back, the problems were paper tigers

(B:43:2) lot of the things were paper tigers, sexuality and the different life - for the last 34 years I've had a different life really...

Has been happy despite the illness

(B:43:11) I'm quite happy with my situation and I don't feel I've missed out in anything. I don't feel I've missed out. For me the big one really was sex, that was the big one, you know and I've sorted that out really.

Participant C – Individual Depiction

(C) is in her mid-thirties, and has experienced a range of psychotherapies in different settings between her teens and the present. (C) had been told in hospital that it was likely she would be in care for the rest of her life. However, she found that by exploring the meaning of her experiences with peers and in psychotherapy, that she has been able to address the traumatic life experiences that have expressed themselves as psychotic symptoms.

(C) was sexually abused by a vicar when she was a child, and started experiencing hallucinations in her mid-teens. She began to believe she had an alien living inside her, and would sometimes see a monster staring back at her when she looked in a mirror. She began to self-harm and was treated for depression and anxiety with anxiety management plans and CBT. This did not address the underlying issues, although CBT gave her some tools to help with her thoughts. At university she began to have flashbacks to her sexual abuse and this was accompanied by three persecutory voices. (C) was then hospitalised, diagnosed with schizophrenia, and treated with antipsychotic medication. This had severe side effects, and deepened her anxiety, which then exacerbated her psychotic symptoms. Later, she acquired a BPD diagnosis, because she feels she was too vocal about how her treatment was not helping. After hospital, she was treated with CBT by a CPN who used a manual for guidance. (C) found this simplistic and rigid, so did not continue. She was then treated in a therapeutic community for borderline personality disorder, which was structurally uncontained, and not able to cope with her psychotic symptoms and suicidal feelings.

Recovery started for (C) when she was encouraged by a local support network to think about the meaning of her experiences, and to look beyond the perception that she was suffering from a biological illness. This became the impetus to become involved in HVN and to take charge of finding a therapist for herself. Initially, she worked with a trainee psychoanalyst, but (C) felt she was unable to cope with her disturbing experiences. However, a more experienced male psychoanalyst helped her feel more contained, and she relished being able to explore her experiences without having them carved into symptoms and diagnoses. For example, this therapist suggested a link between the feeling of an alien inside (C), and the feeling of the abuse she had suffered as a child. This approach helped (C) arrive at her own meanings, rather than having her experiences explained. This led to (C) realising she needed to come off all medication in order to both experience the emotions that it quashed, and to become more involved in work. However, her psychiatrist was resistant, and her anxiety had such a powerful effect on (C) that her psychotic symptoms began to intensify. During this time, her husband was a valuable support, and eventually, (C) was able to come off medication altogether.

(C) continued this meaning making journey with a number of psychotherapists, which more recently have included a DID therapist and an art therapist. (C) has found naming her voices useful, because this helps her to bring the traumatic experience that each voice, or personality, represents back into her conscious mind. In recovering meaning in this way, (C) feels that it would be impossible to ever spend time in hospital and believe that she was schizophrenic again. She now works as a project manager for a mental health service, and is involved in mental health activism.

C1) Participant experienced trauma before diagnosis of schizophrenia

Participant experienced a first phase of trauma in childhood

(C:34:11) As a child, I guess I felt really vulnerable and really wrong, really bad and terrified and yeah, no control, and that's all I knew from quite a young age actually... (C:70:3) I was abused by a vicar when I was like 7, and part of a lot of people in my community were abused. The family-related stuff I find much harder 'cos I'm still... It's like I know that my mum was abused by people and that she was really traumatised. The idea that she might not have protected me from those people is quite frightening.

Early way of coping with trauma was to suppress it

(C:44:1) I think I really hid all the stuff in my childhood, so no one knew. I had like when I was 14, 15, sort of teenage, I believed that I had an alien inside me and that alien was gonna do bad, make me do bad things, or it was going to be bad in some way. I still wouldn't talk to people about it and I kept it all in.

Participant experienced a second phase of trauma in adolescence

(C:70:2) I was raped as a teenager.... (C:46:1) after dropping out of university and- I told people about the rape I had in my teenage years, because that was, I was suffering with depression, I felt crap, I was traumatised. And I was struggling to wash and look after myself and I was self-harming a lot, so I needed to drop out (*of university*), so I gave people that reason.

C2) Psychotic symptoms appeared in late adolescence/early adulthood

Voices were triggered by memory of sexual abuse and rape

(C:44:7) I think I saw a poster saying that you could say no and obviously I hadn't been able to, and I'd had a lot of other traumas, not just the early childhood stuff, but throughout the whole childhood teenage (experiences), like layer upon layer. And that just triggered it. I started to get flashbacks. I started to get, hear 3 horrible voices, and get very paranoid again, (and to) believe the alien conspiracy theories, and it all just disintegrated.

Previously had thought voices were people talking about her

(C:45:2) it was the first time I *realised* that I heard voices. I always thought it was people talking about me and so I may have heard voices pre that, I think I just had visions and unusual beliefs which aren't really unusual contextually.

C3) Initial contact with mental health services was not helpful

Participant had been afraid to speak about psychotic symptoms and so was being treated for anxiety and depression

(C:83:1) initially this psychiatrist was treating me for anxiety and depression 'cos I hadn't told him. This was up in S**** when I was still a student, so he referred me to an anxiety management programme that I couldn't actually attend 'cos I was too anxious! So then I had individual CBT with a psychologist, and again I had maybe 2 sessions before she realised something was not quite right.

When psychotic symptoms became apparent medical treatment was felt to be necessary

(C:84:4) she (*the psychologist*) was getting to the point of considering recommending that I get sectioned 'cos of self neglect because I wasn't looking after myself.

Participant's distress was seen as symptoms of a medical illness - this was initially a relief

Illness became a useful way of explaining experience for both participant and psychiatrist

(C:49:1) (The first time I told the psychiatrist) about being poisoned and followed and all this other stuff. And the voices and everything and they were really nice. They actually said, "It's ok, we know what's wrong with you, we see this a lot in people who go to university, you know, it's ok. Come into hospital, we'll just start you on some medication and get you back out there", kind of thing so it was like, "Oh" (*relieved*)... That felt like the nicest thing someone could say to me. It's like, "Wow, someone understands. It is me, I'm *ill*, but you know, someone can make me better."

Participant initially fought to be given the schizophrenia diagnosis

(C:50:1) I wasn't diagnosed straight away. I was in hospital for about eight months, but I was actually fighting for a diagnosis 'cos I knew what it was by that point 'cos I'd been around people.

Psychiatric medication was the only form of treatment on offer, and had mixed results

Medication was helpful, but had physical side effects

(C:54:1) (I) started on Olanzapine. Massive weight gain, I put on like about five stone - more than five stone - in eight months... (C:54:15) Tried me on Haloperidol, I had ocular crisis, which everyone thought was anxiety, and gave me more Haloperidol to deal with that (laughs). So I ended up in A & E with my eyes rolling back and not being able to breathe... (C:55:1) eventually it was Quetiapine was the one I settled on and that was the one that suited me quite well actually. I had sedation, I had, occasionally would get shaky, obviously the weight gain - I'd gained a lot anyway - got diabetes from the Olanzapine probably, certainly got diabetes on my first admission...

Medication reduced symptoms but didn't address underlying issues, which increased feelings of panic

(C:54:3) (Olanzapine) seemed to work really well, but then I was still paranoid underneath it 'cos I still believed in the conspiracy but I didn't know that I wasn't meant to *not* believe it. No one had told me really what recovery was, so they were like are you feeling better? "Well yeah, the voices are less and this is better, but I still believe in the aliens". And then was released and thought I was being followed, got really panicky, told someone at the day centre and then got re-admitted again.

Attempt to medicate symptoms triggered more symptoms

(C:48:1) I think I had some Valium and Lorazepam-type stuff, but old style antidepressants, like Miltipaxin, which is quite sedating. Seroxat which made me dizzy... (C:48:4) I hated the feeling of being chemically altered. It generally made me quite paranoid. And I don't like feeling my senses are dulled, 'cos it doesn't feel safe then. So that generally triggers more things for me. (C:54:8) Changed my medication

to Risperidone I think, then started lactating which I thought was evidence of the aliens because I was like getting breast milk and no one had told me it was a side effect and it took a nurse to recognise that...

Didn't talk about side effects because they were better than the experience of psychosis

(C:55:5) If you'd asked me what side effects I had, "I'd have said oh it's alright, it's just I'm a bit tired in the morning." I wouldn't have told you about, 'cos I thought, "Well that's the treatment for my illness. What else is there?" And actually that didn't seem as bad as the horrible things that happened when I was experiencing in the psychosis, so you know, it didn't seem important really. But yeah looking back now I had loads of side effects.

Medical treatment impeded recovery

(C:118:1) I'd previously believed that the meds were keeping me 'well' 'cos I'd believed I was ill and I always thought I'd need meds for life, and I'd been told I'd need meds for life. (C:87:1) I think going into the medical sort of system and getting the diagnosis eventually through that, that sort of halted the therapy, so I'd have little bits of counselling, but then there was no counselling or therapy while I was an in patient or - even when I was sort of discharged, I was discharged to a CHMT...

Treatment in a residential therapeutic community was unhelpful

Therapeutic community ideology was too rigid

(C:104:6) I think perhaps they were so focused on that particular approach of everything being group, that there was no room for the individual...

Therapeutic treatment model that saw itself as reflective, but was in practice not, and meant that practitioners were less able to see their lack of reflectivity

(C:104:14) it's almost like the model itself they thought had reflection inbuilt and they really weren't thinking about - I don't think they were thinking about - what was wrong with me in the place... (C:104:12) (there was) a lack of reflection about their part in the power...

Treatment in a therapeutic community felt uncontained

(C:99:1) that was hell. That was like being in a Big Brother House, full of very traumatised people... (C:100:2) I can kind of relate to a lot of people and I think I don't have the outer skin, I used to not have the outer skin there, and so I'd carry so much of other peoples' traumas, so it's like flooding really. And the staff just didn't handle it particularly well. So it was, it was really uncontained and really unsafe.

Hospital and therapeutic treatment settings were re-traumatising

(C:160:6) I think the therapeutic community and hospital environments were just really re-traumatising and, and made everything that much worse.

C4) The psychiatric system of diagnosis is problematic

Diagnosis focused on symptoms and ignored underlying issues, which participant felt were more important

(C:85:3) I had really sort of intense beliefs about aliens and being followed and I was seeing things and hearing things and it was all very, very intense... (C:84:11) I saw a psychiatrist and they actually asked the question about the unusual experiences and I told them – not everything, but I blurted out quite a lot and that's when I got the diagnosis... (C:8:10) I've been traumatised, that's my way of boxing things up and it's going to come out when these things come out...

Psychiatric diagnosis often reflects arbitrary criteria that do not relate to human experience

(C:2:2) I've had the diagnosis of schizophrenia and it tends to swap between the two (*schizophrenia and schizoaffective disorder*), depending on which person speaks to me. I also have dissociative disorder, in inverted commas, some people say that's dissociative identity disorder and that's probably gonna be my new diagnosis, as well as schizoaffective disorder and also occasionally I get diagnosed with personality disorder, depending on how people feel about it... (C:9:13) it seems artificial and stupid to be trying to distinguish it. It's just human experience.

Diagnoses are often treated in a rigid/inflexible way

Psychiatrist felt unable to work with participant's emotional content because it did not fit the diagnostic picture

(C:58:1) It's like, "I'm here to talk about your beliefs, your delusions, your voices. And it's ok you can feel distressed in relation to those, but if you start to feel like too emotional or too reactive or whatever, then that's like, that's not about the biological, that's something different."

Psychiatrist fixated on medication as only treatment for schizophrenia diagnosis

(C:61:3) sometimes she'll (*psychiatrist*) sort of not plead with me, but very emotional, "Are you ready to go back on the meds now, (Participant C)?" (C:61:7) And I'm like, "I'll accept your help, I'm just not accepting the medication, 'cos I don't think that's helpful for me, but I'll do other things, you know if you give me a CPN or something to talk to, that would be fantastic". She's like, "No this is the treatment and you're not having a treatment for your illness." Really frustrating.

Once given it is difficult to get the diagnosis changed

(C:111:14) once I'd got stable I got myself re-assessed because I wanted to get rid of the BPD label... (C:111:18) My psychiatrist refused to see me as anything other than BPD, he just, yeah, he just wouldn't.

When patient in residential therapeutic community for BPD participant found focus on diagnosis unhelpful

(C:102:4) they weren't set up to believe that I could be experiencing sort of so-called psychosis, they didn't know what to do with that part of my experience... (C:99:7) I was seen as having BPD... (C:99:12) but also they believed that I wasn't paranoid and I wasn't hearing voices, and that I was just taking on an illness identity. Which was hard because the more I was in that situation, the more paranoid I was feeling...

Participant fears talking about difficult feelings with psychiatrists in case given a BPD diagnosis again

Careful when talking about emotional content with psychiatrist because that might bring back BPD diagnosis

(C:5:2) with psychiatrists I have to be very careful or I feel I have to be very careful about what I tell them or what I don't tell them... (C:5:5) it was, "Ok, I don't wanna be labelled BPD so I'm not going to talk about feeling unstable, I'm not gonna talk about this other stuff", because I don't want that diagnosis...

When challenging psychiatrist about schizophrenia diagnosis, was regarded as difficult and was given a BPD diagnosis

(C:60:9) I just asked her, "Have you got any experience in sort of like treating people with dissociative issues like myself? And she said "I'm not gonna share my CV with you". And I was like "No, I'm not asking to see your CV". She said, "I'm not justifying myself to you". I said, "I know I just wanted to know, 'cos I know you have the schizophrenia stuff, but I wondered if you'd come across this and whether, I wanna know if I can talk to you about it." And she was like... and she refused to discuss it with me and felt very challenged... (C:60:16) she also said after that I had BPD.

Diagnosis affects the way you are seen by others

If you have BPD diagnosis you are seen as manipulative and people stop listening
(C:58:8) being labelled with that (*borderline personality disorder*) was really horrible. People stop listening to you, they stop believing the things you say and what you feel... (C:112:9) I felt, if I had the choice between either being seen as a personality disorder or as someone who is ill, I prefer the ill, 'cos at least people listen to me. Whereas with personality disorder I think they'd stopped listening.

Participant was warned about the danger of receiving the schizophrenia diagnosis
(C:51:3) an OT who I had a good relationship with, said to me, "You know, you don't want the diagnosis, don't ask."

Participant is able to work despite having 'hardcore' psychiatric diagnoses

(C:6:1) I've just gone through a load of lengthy assessment process, at the Maudsley's Trauma Clinic and that's what they've come up with (*dissociate identity disorder*), so yeah it's kind of funny that I'm now holding some of the most hardcore psychiatric diagnoses, yet I can work five days in a week and I'm actually pretty sane.

Diagnosis affected the way participant saw self

Schizophrenia label reinforced pre-existing poor self-image

(C:42:1) no wonder I ran to that label and believed I was schizophrenic because it was like - "Yeah, I am wrong, there is something really bad underneath the surface that no one else can see". (C:42:4) And that did so much damage, it's taken me a long time - even before therapy - to kind of start to undo that.

What professionals want to hear informs the way you see yourself

(C:4:5) I've kind of bought the delusions and hallucinations to the psychiatrists and stayed away from the trauma and brought the trauma to the trauma people, and actually now I've started to talk more about the voices to them, but it's almost like

what they want to hear is what frames your experience when you're with them. So it encourages you to split things off I think a bit more than is really helpful.

Participant dislikes diagnostic labels but acknowledges that she is still caught up in them

(C:112:2) they decided I was either schizophrenic or schizoaffective, but certainly not BPD, just with sort of post trauma stuff. Which is a complete joke 'cos it's just labels, but those labels were a lot easier to bear than BPD I think. And I had to change my psychiatrist 'cos he refused to agree with it. He was just like "No, this is all crap." So I got a new psychiatrist...

The power of the diagnosis mirrors the dynamics of past abuse

(C:38:4) I think schizophrenia's irrelevant. I actually think it's colluding with the abuse, I really passionately believe, really believe that if we talk about schizophrenia we're locating the problem with an individual and we're neglecting society, whether or not they've been through the traumas that I've been through. There's been stuff that's happened to everyone that gets that diagnosis and by saying it's them, it's biologically wrong. Even if you're trying to help them it's just reinforcing the abuse and the trauma that they've suffered their whole lives... (C:40:1) You're being abused because people think you want it, you're bad, you know, yeah. It's that you're the problem, not the abuse. It's, you've done something wrong, and you feel that very keenly as a child and I grew up with this sense of me being the monster...

Service users often identify closely with their diagnosis

Separate service user cultures have evolved with different diagnoses

There are shared languages to describe experiences with different service user groups. Different languages are needed when talking with trauma professionals, or psychiatrists. (C:5:15) if you're kind of quite confused about who you are anyway, (it) can just make you feel you're not quite being yourself with all these three different, or four or five different groups.

Participant fears losing schizophrenia diagnosis because of losing peer identification

(C:7:7) I was worried about getting dissociative identity disorder diagnosis because suddenly that separates me from the Hearing Voices Network and it's like, "What do I talk about - my alters?" There's a whole language used with that diagnosis that I don't feel comfortable with. And, so yeah, it freaked me out.

Service users guard the separate diagnostic identities as much as professionals

(C:9:1) I think, people with schizophrenia, have spent a lot of time, I've spend a lot of time trying to tell people it's not split personality, this is an illness, or it's a response to trauma... (C9:5) and like the people with dissociative identity disorder have been going, "Yeah, but we're not schizophrenic, this is trauma related, this makes sense and at least we're not like those crazies." And it's like they've developed separately.

It is problematic when diagnosis directs treatment, not the underlying issues

There is a split between a biological lens and the trauma/experiential lens for looking at the problem and neither addresses the whole issue

(C:3:1) I think it depends on the person who's speaking to you, the glasses they're wearing, so the psychiatrist will see me very much in terms of having a biological mental illness that, because I supposedly have primary delusions, i.e. I believe some

really weird stuff and have very extreme experiences and my voices are third person stuff, then that means I've definitely got a biological illness and they'll see that part of me, but I also won't tell them about my emotional side because I don't wanna be diagnosed with personality disorder, so when we have those communications we talk very much in terms of the illness... (C:3:9) But the trauma therapist or the trauma psychiatrist or psychotherapist will see me in terms of things that happened in my life and then rather than see the biological illness, they'll see the sense in it and see it more as dissociative experience. ... (C:106:2) it's a very medical, sort of simplistic way and it's almost like they can't see the extent that the trauma's affected me, they couldn't... that all my self harm and all my kind of post traumatic stuff was seen as like part of the schizophrenia. And then they switched their glasses and saw the BPD and the trauma part and then couldn't see the schizophrenia part, but I thought while they're looking at the trauma part, perhaps someone will help me... (C:3:14) But with psychiatry both of those diagnoses (*schizophrenia and BPD*) means that I'm not open to psychotherapy.

Rigid diagnosis prevented appropriate treatment

(C:155:9) it's almost like the box itself of being schizophrenic stops people from thinking and the box of being borderline stops people from thinking and, even the box of being disassociative can stop people from thinking I think... (C:156:1) I just wish they'd get rid of the boxes, because diagnoses are meant to help you get the right treatment, but what they seem to have done for me, at least, is help me get the wrong treatment and prevented me from getting the support that I needed. Which is really damning I think. And it does make me feel angry...

Participant altered what she presented in order to fit, or avoid certain diagnoses

(C:113:1) I had to squish down, to kind of keep that diagnosis (schizophrenia diagnosis), to make sure I didn't get labelled with BPD again, it meant I never talked to any (psychiatric) professional around my feelings or the trauma.

Difficult to name countertransference in the treatment relationship fed into the diagnosis and treatment

Participant's internal personalities created strong countertransferences that many professionals were not equipped to recognise, or work with

(C:163:4) I created so much conflict and confusion in the people around me, not intentionally but because there was all these different parts of myself trying to be heard, and my identity was confused. That people had very strong feelings about me, but even therapists and even people that were meant to reflect on it didn't. Even my last therapist, who's supposedly the best therapist in the universe - not quite, but she's a respected, famous therapist - found that hard to see her part in it. It was all about me...

Difficult to name countertransference reinforces Personality Disorder diagnosis

(C:60:2) If somebody feels like a weird emotional reaction to you, because they're picking up on something, that means you've got personality disorder, if it's something they can't put their finger on that means it's personality disorder... (C:94:2) if you're a nurse in a CMHT and you've got an unusual feeling about a client, what do you do with that? You could tell your supervisor but then your supervisor might or might not be understanding about that and you might also feel de-skilled. (C:94:7) I think if they knew what my issues were it would be quite obvious that I needed someone that had

that kind of support and could name those un-named feelings and work them through themselves.

C5) Psychiatric system of diagnosis was more helpful when it took participant's wishes into account

Being assessed for dissociative identity disorder made sense of previously hard to fathom experiences

(C:139:5) they gave me the SDQ Somatoform Disassociation questionnaire as well as the DES, the Dissociative Experiences scale, and I filled those in and I actually scored massively highly, especially on the Somatoform one. And no one had ever asked me those questions, all these weird body experiences I'd had, I always thought I was like freaky. When I was a kid I thought I was maybe severely ill and I would just spend my whole life... and no one ever spoke about them, just like no one ever spoke about my voices and then I got, I can talk about my voices 'cos I've got a language.

Participant wanted to replace the schizophrenia diagnosis and the dissociative identity disorder diagnosis seemed a better fit

(C:140:3) I wanted to get rid of the schizophrenia label I think also. I think it had done its job and it was like it stopped everyone from seeing me... (C:6:8) back in sort of five or six years ago, I would have jumped at that diagnosis (*dissociative identity disorder*) and not kind of changed the way I acted based on it, but changed the way that I understood myself based on it. So it would have re-framed a lot for me...

(C:8:2) I'd have looked at my experience and gone, "Ah, these are alters (*alter egos*), this is true because there are experts telling me this", and it would have changed how I saw my internal world.

C6) The first phase of recovery started when participant's experiences were taken seriously

Encountering professional and peers support bodies that encouraged participant to understand meaning of psychosis was helpful

(C:71:15) Network for Change, they were - and the Hearing Voices Group - they were like huge 'cos they were the first people that really said, "There's a meaning here, there's something, this isn't just an illness randomly grabbing you and dragging you like a demon into hospital where other people make you better. There's something here".

Peer support networks encouraged independence, but participant found it easier to see herself as ill initially

(C:72:3) The first time that someone mentioned that the voice might be representative of an abuser - my abuser - I was really angry at them. So I wasn't ready for it. Still not entirely ready for it... (C:157:13) I was really resistant to this (*peer support*) for the first couple of years, this was when everyone else was doing it, running around me going, "Look there's another way!" And I was like, "No I'm ill!"

After exposure to peer support networks, participant stopped believing that the psychiatric system could help

(C:111:5) I kind of dropped out of services, I kind of took, I realised that I wasn't gonna get any help through the psychiatric system and it was making me worse, not because they wanted to, but just because I was continually not getting any needs met... (C:111:10) once I had the stable support all of the kind of re-triggering stopped and my difficulties with people, my self harm sort of reduced and I stopped self harming...

C7) When psychotherapy has been unhelpful

Participant frustrated that she had not choice in form of therapy that was offered on NHS

Participant offered CBT because it was recommended in NICE guidelines for psychosis, but had experienced it before and felt it wouldn't be helpful

(C:130:1) NICE guidelines say you offer CBT for psychosis 'cos it's effective and, yeah, evidence-based treatments... (C:129:10) I've studied CBT for psychosis and I know the tricks and there's no point in me going into CBT therapy really – it's not gonna teach me anything.

Participant engaged with experienced psychoanalytic psychotherapist, but was rejected at assessment because deemed unsuitable

(C:108:3) (The assessing psychoanalytic psychotherapist) rejected me for therapy because of my 'poor ego integration', which I didn't realise why until I got a letter about, well a few years later... (C:108:7) I was like, "What do you mean by poor ego integration?" I still don't know what he means by that. But yeah I guess for whatever reason I was too vulnerable for therapy, or he thought I was too vulnerable for therapy.

Working with inexperienced or poorly trained therapists was not helpful

Participant felt rejected by university counsellor who seemed unable to cope with participant's psychotic experiences

(C:76:3) at university I saw a counsellor and that was because I was self-harming and struggling and the GP kind of encouraged me to go and see someone. They got a bit freaked out... (C:79:3) as soon as she realised it was something she felt she wasn't able to deal with, she then got rid of me, which was probably because she just couldn't, it just felt like she wasn't sure what to do.

CPN attempting to deliver therapy from a CBT manual was unhelpful

(C:87:4) I had a nurse who tried to do a bit of CBT for psychosis for me but out of a book! (C:87:4) It just felt like why are you working through a book with me that's full of really cheesy ideas that don't relate to me at all... (C:89:3) she didn't appear to be very confident in what she was doing. So yeah, I guess I didn't have much trust that she knew what she was doing either...

Desire to please CPN/CBT therapist by playing along with exercises didn't help

(C:92:1) it's a common thing for me - certainly in my early days of therapy - is to try and please the therapist and the whole me feeling that I needed to actually produce an example and work through it the way they wanted to, didn't help.

Trainee psychoanalytic therapist wasn't able to help participant process difficult material that emerged

(C:132:6) I mean we had nice chats - but we didn't get anywhere... (C:11:2) We'd talk about the voices and what they said and we'd talk about – there was a time when I was feeling very paranoid, and like J*** (*husband*) had been replaced and my job was kind of like a, it wasn't really my job, this was part of the experiment so it was part of the alien stuff. And I was feeling quite distressed and I do remember talking to her about that, but we didn't really, it didn't go anywhere... (C:132:9) we weren't working through anything, we were just treading water... (C:134:19) I felt she just didn't wanna go there or couldn't go there and I think that's, yeah, I just disappeared at that point...

Trainee psychoanalytic therapist didn't know how to respond to participant having dissociative experience in the therapy session

(C:134:15) I think the few times I disassociated with her, she didn't know what to do with it and so she was sort of, I got the feeling that she was a bit unsure how to handle things and I kind of went, and I didn't feel safe, I lost my sort of - I lost trust in her I think...

Participant felt she had to protect the feelings of trainee psychoanalytic therapist

(C:137:1) I think it was me that made the decision to terminate therapy and get someone else. I wrote her a lovely email... (C:137:4) it was a Dear John letter really and I was very careful to protect her feelings 'cos I also knew she wasn't properly qualified, she'd only just qualified at the end of our therapy.

Rigid application of therapeutic theory model was unhelpful

CBT was mechanistic and rigid: participant felt she had to lie to fit the model

(C:88:5) I had to try and think from the week before what example have I had when I've had a strong reaction and my voices have got worse and relate something, so I'd usually give a false example 'cos I couldn't think of anything. ... (C:88:12) it was coming from a completely disjointed place because it wasn't a real example and my examples wouldn't have fitted into that but there was no talking around it or kind of exploring what it meant to me – it was a conveyor belt, it just felt really prescribed.

Change in participant's diagnosis changed the way the CBT therapist responded to participant

(C:93:5) I went for about 6 – 8 months diagnosed with BPD before I got the schizophrenia thing back again, and once I got labelled with that during the course of my work with her, she changed dramatically, 'cos - again my perception of this is that it gave her a word for the un-named feeling that she had and then she could put me in a box and say, "This is personality difficulties coming out here, this is why I feel uncomfortable and why we're not getting very far with it."

Trainee psychoanalytic therapist's adherence to basic techniques, such as repetition felt distancing

(C:137:6) there was loads in the therapy that was really difficult, like she'd just repeat what I was saying sort of the echoing thing without the, it didn't feel very validating 'cos she'd just repeat the end of the sentence. And all of those little things, plus that just made me feel very, just you don't know what you're doing.

Dissociative identity disorder therapist's rigid adherence to psychoanalytic attachment theory seemed to satisfy therapist's needs, not participant's
(C:151:2) she was going through a model and hers was, "It's an attachment thing, you need to attach to me." It was all about her, attach to her...

Not voicing personal feelings about therapist often brought therapy to an end and was unhelpful

Gender of experienced psychoanalytic psychotherapist and layout of the room provoked past trauma which participant felt unable to discuss

(C:23:1 – C23:8) *Therapist's (male) gender provoked memories of rape for participant. The therapy room felt confined and brought up feelings of being trapped for the participant.* (C:23:9) I struggled with zoning out a lot and struggled to kind of stay around in a session and I kind of realised that actually having a male therapist that I couldn't really easily get out of the room in was a slightly stupid idea for me.

Participant felt Dissociate Identity Disorder therapist was inflexible at times and couldn't admit to being wrong

(C:146:5 – C:147:7) *There was a confusion over the time of the session and participant became anxious that something had happened to the therapist, which in turn, provoked an anxious response from participant's voices.* (C:147:1) And then she got angry with me on the phone 'cos she thought that we were seeing each other later on that day and, yeah, she felt that I was... (C:147:4) trying to avoid the therapy by telling her it was the time when it wasn't...

Unspoken power dynamics in therapy brought up memories of abuse

(C:13:5) I'm used to having psychiatrists that can section me and give me medication and not challenging and be very passive within that for fear – that's my childhood, and that's where it is now. So in therapy I would do things like I wouldn't ask to use the toilet, 'cos it's a horrible boundary cross for me to use the bathroom in the therapist's house...

Not able to trust therapist was an obstacle

(C:15:12) I've been in therapy for over a year now (*with Dissociative Identity Disorder therapist at time of first interview*) and I still don't trust her and she knows I don't trust her. I like her and I kind of, I feel, I experience her as really unstable - she feels very unstable to me and she feels like she's contradictory...

Feeling pressure to work at therapist's pace was unhelpful

(C:145:7) the (Dissociative Identity Disorder) therapist was also a very strong personality and I felt she pushed a lot and had ideas about what this meant that I don't want to think about yet... (C:145:10) I want to work my way around it, I don't want someone else telling me that this is real and to deal with that, I wanna feel that I'm making sense of it myself... (C:146:2) "Why aren't you trusting me yet?" That kind of almost desperation she seemed to be feeling. And it just started to, yeah I didn't feel safe again.

Feeling uncontained in the therapy environment felt unsafe

(C:143:9 – C:144:4) *During therapy drawing was used as a medium for participant's voices/internal to express themselves and recall experiences of trauma. The participant felt that she wasn't consciously present at these times and had not yet*

processed the content of the pictures when confronted with them at a later session because they had not yet been cleared away.

Seeing multiple therapists has made participant wary of psychotherapy

(C:149:1) I think the whole idea of going to so many different therapists has made me really cautious about therapy.

C8) When psychotherapy has been helpful

In working with a trainee psychoanalytic therapist, participant understood better what she wanted to get from psychotherapy

(C:24:7) she (*trainee psychoanalytic psychotherapist*) knew that we hadn't got anywhere, I knew we hadn't got anywhere, and it was really good because what she'd helped me do was realise was that now I feel ready for the therapy, but that I need to find somebody else to have that therapy with.

Some CBT techniques have been useful

(C:95:2) *CBT therapist who participant saw initially for anxiety and depression, gave her a handout on the traps of thinking.* (C:95:5) I recognised a lot of them and it didn't- it wasn't like a hallelujah moment, but throughout the rest of my life I've often thought about catastrophising and the different things we can get into.

Participant sought private therapy because she wasn't offered therapy of choice on the NHS

(C:138:1) I actually paid for a private assessment. I didn't, wasn't actually planning on doing that, I was just trying to seek a therapist that was ok with that kind of disassociative stuff and wouldn't freak out of me and also was ok with the voices.

Working with an experienced therapist of participant's choice was helpful

(C:22:3) I found an experienced therapist, but a male therapist, who taught at the B**** Centre, and I found it myself, I had control of it that way which is great...

(C:22:6) I could talk to him about some stuff and he did really look into things with me...

Feeling able to challenge and be challenged in the therapy was helpful

(C:14:1) I've got a really challenging relationship with my current therapist (*current at time of first interview, not second*), that I can challenge her and I have. We've had - not arguments - but disagreements and I will use her toilet and I will talk about money and I will say if I think she's said something that I've found quite hard to listen to or quite disrespectful, or the language that she's used and I'm able to do that, and that's brilliant. (C:30:2) With this therapist (*Dissociative Identity Disorder therapist*) when that happens (*when participant retreats into psychotic belief system*) - it still happens sometimes - she's a bit more challenging actually, she respects that I might need to think that at the moment... (C:30:5) but then she kind of goes, "Well, this stuff is hard, you might not want, people might have been very duplicitous in the past."

Not having to engage with the framework of diagnosis was helpful

(C:57:1) The good thing about therapists is they're not about to diagnose you. Especially a therapist you pay for. "She's working for me!" This is how I remind

myself. Yeah, that's it. Emotions were something I feared within psychiatry and they were discouraged.

Being able to develop a more equal relationship with therapist felt good

(C:148:13) (My current art therapist is) kind of a bit more across from me, she's quite down to earth, she's got a piercing and she's got ADHD, which I quite like because she's quite fidgety, which stops her being the calm therapist with the tilty head. So I feel, by her being slightly chaotic, but also being really good at recall at what I've said previously, and quite respectful.

Developing a sense of trust in therapist encouraged participant to explore traumatic material

(C:80:10) before I build a relationship with a therapist, it takes me a long time to really feel there's some trust there, so I take spend a long time sussing it out...

(C:78:1) I'd been so used to keeping secrets for my whole life, that the idea of talking to someone about it just seemed really alien. (C:92:7) It's taken me a long time to even mention unhappy things to therapists, I've been a very compliant – probably a pleasure to treat. (C:43:3) (Because the fear is that) once they see past the nice person, they'll just see all this yuk that came from your childhood that will be really bad for them, they won't be able to cope with it. (C:16:12) the more that I and my voices see that she doesn't do anything terrible to us, no matter what we kind of bring, the more I'll be able to trust her. And once I can trust her we can go a bit deeper into some of the stuff.

Being able to work at own pace was helpful

(C:149:4 – C:149:10) *Following an intimate medical examination, participant's voices expressed murderous intentions towards her cats, who participant saw as a metaphor for vulnerable aspects of herself.* (C:149:10) what the other therapists would have done is made me go into the why and what the voices were remembering and what it was, but she didn't which I thought was really good 'cos I was scared about mentioning it in case we went back into it 'cos I'm not ready at the moment.

A more open and reflective, less directive, approach to the therapy helped participant make her own associations

Experienced psychoanalytic psychotherapist helped participant make her own associations

(C:107:13) I described the person who abused me as kind of like cold and sort of a bit alien, and he just made the link between that and my alien... (C:107:20) Whereas (*where other therapists may have been more directive about a link*) he did it in a way that was just wondering if there was a link, rather than "I wonder if the alien is your abuser?" It just felt helpful.

Art therapist helps participant make her own associations at her own pace, which is felt to have less potential to be re-traumatising

(C:148:1) (Current art therapist) works with disassociative clients, so she gets the whole disassociation part, but she's also not a purist, she's not kind of a fanatical disassociation person. She's more about helping you process stuff in time...

(C:148:12) It's much more about processing and not re-traumatising. I think the other therapy re-traumatised me a bit, unintentionally. And I feel a bit safer.

Being able to explore experience, rather than receiving directive interventions has helped participant to 'bring trauma back' into self rather than dissociating
(C:154:1) I think sometimes just exploring it from different angles in an arty form helps me work out what I feel about it and integrate it 'cos I don't want it to be split forever. I figure these are my memories and these are my experiences, and I just wanna get to the point where I feel safe enough to bring them back into me, rather than have them as separate...Weird.

Therapy helped participant explore feelings underlying symptoms
(C:41:6) certainly from therapy, what's come up loads is the idea that I just feel that inside I'm just a squishy black mess of badness and that if anyone really sees what's inside me, that's it. They'll get bad, or someone will hurt them or they'll just reject me or hurt me and I deserve it.

Being able to openly explore issues of power and trust in therapy relationship has been helpful

(C:16:4) I'm able to challenge her and kind of say when I think she's being inconsistent or when she says I'm doing really well and I'm actually doing really bad and she's worried about me and that happens within a session I'm just like, that sets me off, that sets my voices off and my voices start talking about her a lot. But by being able to talk to her about that and how I experience it then, it's slowly building a little bit of trust...

Feeling listened to and understood by therapist felt therapeutic

(C:95:10) *Feeling that CBT therapist who treated participant for anxiety and depression cared and tried to understand, was important.* (C:96:1) 'cos at that time I didn't care about myself and I didn't feel – I think I probably felt that there was so much about myself I was hiding I felt a bit fake.

Therapy helped participant to understand psychosis as a survival mechanism to escape from underlying trauma

It was less painful for participant to think of abusers as literal monsters
(C:34:15) (As a child) What I was escaping from was the people who were hurting me, and so instead of having people who were hurting me as being people, they became monsters or aliens or *things*, separate. (C:29:3) Talking about it now I can see it makes so much sense 'cos I didn't want it to be real, and I have a very metaphorical kind of brain, so some people might be, "*As if* this is happening", for me "*This is* happening", and it gave me a lot of comfort actually.

Confronting trauma in therapy has been painful, but has helped participant understand psychosis as a form of disowning traumatic experiences

(C:28:1) Therapy's confusing. Therapy for me is like having your insides ripped out and it hurts so much, it hurts more than I've ever, ever thought anything could hurt, looking at your stuff as having meaning hurts it's a lot easier to talk about it in terms of alien conspiracies and kind of - one time I went saying I'd kind of started to believe that I was, *Bladerunner*, yeah, after something I've been in therapy for maybe a few months, I kind of went, I'd started to believe that I was one of these, I can't remember the word, but yeah these *Nexus 7*, whatever it is. Which basically meant that I didn't have a history and that I was basically made and all of this stuff that I was

remembering, all the bits my voices were remembering weren't real and I was just given those memories and that I'm not human...

Psychosis is only marginally better than the traumatic reality it defends against
(C:33:1) it's not a fun refuge, and that's the problem, it's like you'd imagine if I was creating this as a refuge it'd be full of flowers and bunny rabbits, but actually it's tortuous it's not fun. I feel very powerless, I feel that – yeah I don't trust reality, and I just get very stuck, but yet weirdly enough compared to the reality of why I feel powerless, that's better, it's better to have aliens and monsters and kind of robots and things rather than real people and real events that I don't want to think about.

Having understood psychosis as a way of escaping from trauma, it's not possible to go back into a full psychosis

(C:31:2) It's kind of like the Matrix. Once you take the pill, you can't un-see that. You can't un-see this different world and, as much as I'd like to - and sometimes I would like to go crazy again because it'd be easier, it really would be easier sometimes - you can't un-see the sense that you've found in it. I can kind of have a break from the sense and maybe give myself a bit of respite with psychosis, but I can't ever go back... (C:38:1) I don't think I'll ever go crazy again. Not properly. I think I might go through periods of psychosis to get away from all this, but I don't think I could ever spend eight months in hospital and believe I was schizophrenic.

Therapy helped participant to communicate with her voices/internal personalities

Naming the voices helped give them an identity

(C:40:5) Naming the voices has been really helpful to me... (C:40:7) 'cos names are powerful, and you and the voice can choose a name together. And Alfie I chose for her because she was very much Monster Girl, 'cos she thought Monster Girl was actually with the monsters. And she believed that she was a monster and because of the things that had happened to her. She is basically me as a child. I really thought I was a monster when I was little. I saw monsters and I believed I was one. And she still carries that as a voice or as an aspect of me...

The voices characterise aspects of the participant's internal world that are related to traumatic experiences

(C:35:2) It's like Blue, the little girl, her view of the world, or at least her internal environment that I have and where she feels most safe is just in blackness, like in darkness and doesn't like open doors and doesn't like lots and lots of things. Doesn't like connecting with any other people, or even objects, because that's not safe. And it's like, so for her the refuge is just darkness. And it's like, yeah I can see that, so I guess refuge is created from what is the most difficult part of that experience...

Participant came to understand visions as metaphorical representations of how she saw herself

(C:41:1) My first vision that I remember - and I have patchy, patchy memories - but I remember this one distinctly 'cos I was at my mate's house and I was looking in the mirror and I saw this horrible monster looking back at me and I looked round (*laughs*) and my friends didn't react funnily. And I think I kind of figured that was me, and that I was the monster and underneath it all I was a monster.

One internal personality helps express her feelings of stress

(C:36:1) Tommy is the only boy, the only non-nasty boy that I have as a voice and as an aspect of self. He counts, he does patterns and traces the environments – and this is really interesting in therapy actually – this comes up quite a lot, ‘cos the more stressed I get the more I do little patterns as a safety strategy... (C:36:7) And what I know now is that was a way of just ignoring people and the things around me, but focusing on the only bit that was safe.

The traumatic Not Yet voices have an important purpose

(C:37:1) I don’t like them, don’t want them I’m a little bit afraid of them... (C:37:6) They’re representative of the abuse; they’re not the people that hurt me. So – yeah they’re trying to keep me safe in their own way. Or I’m trying to keep myself safe by not talking about these things and by not sharing it. So yeah, once you see it it’s hard to go back from that.

Participant understands abusive voices not as internalised abuser, which would be too frightening, but rather, an expression of the *experience* of abuse

(C:73:1) I think the way I get around that isn’t the abuser’s in me, or anything like that, ‘cos I think that feels horrible. But I think the abuse, the powerlessness, that’s got the voice and that voice remembers what people have told me.

Voices/internal personalities responded to what happens in the therapy

The most traumatic voices were triggered by entering therapy and needed to be suppressed at first

(C:19:1) (The Not Yets) that’s my name for the group, which is kind of the ones I don’t want to deal with yet. So it’s a pushing away strategy that I’ve got, ‘cos they started talking to me about two years ago, very shortly after starting the first lot of therapy...

Internal personalities express their independent feelings about the therapy

(C:26:1 – C:26:6) *Participant’s internal personality, Blue, likes therapist, but is also scared of her.* (C:26:6) And then there’s a teenage one that really hates it, (*laughs*) which is understandable really. Alfie’s just like yeah, she really, really hates therapy and hates talking about all this crap... (C:27:1) She used to try and get me to stab myself actually at the start of therapy for the first six months... (C:27:7) I can understand how some therapists would be like – “Aaaaaah this sounds like it’s setting off more than I can handle here”.

The voices comment on things that participant hasn’t noticed

(C:27:14) there’s like a picture, a picture that was one from my mum’s house, which she just randomly has - same frame and everything which is really, really weird. After three weeks of seeing that there and feeling really weird, I actually told her about it and she took it down. And then the next week she forgot to take it down and I didn’t notice – well, yeah I did notice - but I didn’t notice, and then the voices were talking about it afterwards...

Participant’s voices responded to issues of power and trust in therapy

(C:18:8) (The Not Yet voices, *who participant feels are representative of abusers*, are) very much threatening. Threatening her, threatening me if I talk to her then

they're threatening. That's, yeah, that's actually not that hard to deal with. It's horrible and they're the ones I'm most afraid of, but it's not that hard.

Therapy has made recovery possible

Without therapy, participant felt they wouldn't be alive any longer

(C:71:9) without therapy I really wouldn't have the opportunity to do that (*work through trauma and make it less painful*), so I'd be forever completely subjugated by these experiences. I wouldn't be working and I wouldn't be having a relationship like I do. And I wouldn't, yeah, I wouldn't be here really. I think I might, might not have survived if I hadn't have had the opportunity.

Participant felt that if they had gone into therapy earlier their recovery would have happened sooner

(C:108:9) I think if they had have given me therapy back then I'd have had a quicker journey, because I was ready for it. I think the fact that I was able to listen to him (*psychoanalytic psychotherapist who said participant was not ready for therapy*) and kind of actually think maybe he's got a point at least to me suggests that I could have made use of it.

The struggle to find helpful treatment was a part of the healing process

(C:156:9) if I hadn't have gone on this journey though I wouldn't be me and I feel a lot and have grown a lot through it so, you know, I wouldn't rewind time and then get into therapy sort of like 15 years ago and then not go through this 'cos there's no point. I am me, and I'd be someone else.

C9) Voices and personalities have a meaning that needs to be understood

Participant's voices/internal personalities often express things that participant is not aware of

Participant's voices remember some aspects of trauma that participant doesn't

(C:70:13) Like there's things that I remember feeling and going through in my childhood and also just the things that happened in my family that don't make lots of sense when you look at it and it's really the circumstantial evidence of bad things happening is huge, yet I'm really denially. And I know sensibly that yeah, "Stuff happened." And bits of me - my voices know that, but I don't wanna know that. God, so confusing, and I think it might be a while before I want to know that.

Voices/internal personalities respond to situations without participant being consciously present, leaving her with disorientating feeling that others who witness this hold her awareness for her

(C:153:1) there are times when they'll communicate without me or without my conscious me... (C:153:7) I feel like I leave the building and don't actually know what's happening. And that's ... weird really because it means that other people around me are holding bits. Like the bits J***'s (*husband*) witnessed, he's seen me as a traumatised child in inverted commas in the shape of his wife like, I don't know, batting off kind of people and things and just really, yeah, being freaked. And he holds that, but I don't because I just hold his memory of holding that. And that's just weird as hell.

Helping internal personalities/voices to feel part of a whole has been helpful

(C:150:5 – C:150: 10) *Participant has developed strategies to help internal personalities feel part of a whole.* (C:150:10) there's a lot of body disconnection going so it's a way of helping me feel more connected and help my little ones feel more connected, hence the socks. Because one of my little ones chose the socks and the idea is they can look at them and go, "This is the body, this is my body", not... "This is the body we've gotta keep healthy."

C10) Coming off medication was necessary to further recovery

Participant became concerned about long term physical health risks of taking psychiatric medication

(C:124:4) I read a Joanna Moncrieff article which was about brain shrinkage, and because I have a very vivid imagination, I could actually feel my brain shrinking. I knew it wasn't, but it was almost like it really highlighted the damage these meds might be doing to me and I'd been on them quite a long time.

Participant needed to come off medication to function more fully at work

(C:118:4) I knew that there was no way on all the medication I was on that I could function in the mornings getting to work. (C:119:3) J***, who I was going out with at the time would wake me up, bring me coffee, I'd fall asleep holding the coffee in bed I'd kind of fall asleep, and then he'd take the coffee away and then he'd try and get me breakfast, so bring me some Weetabix or something and then wake me up again and I'd try and eat Weetabix and then have to go back to sleep and then he'd wake me up again and *again*, and eventually I'd be able to get out of bed and it was just – yeah, really hard... (C:122:7) over the course of maybe a year, I'd reduced the dose quite dramatically so I was taking a lot less than I had previously and coping. I was having sort of increased experiences, but I was coping with them.

Participant needed to come off medication to function more fully emotionally

(C:123:5) (Medication) was putting a block between me and the world... (C:125:1) I remember sitting on the sofa with J*** - all within a very short space of time - and just feeling so disconnected from him and just like there was a big gulf between us and it wasn't as if we'd had an argument or anything, I just didn't feel fully present and so all of those things together I just thought I need to get off them now.

Was able to come off medication gradually, with a lot of support from husband

(C:63:1) I stopped like 3, 4 years ago I stopped my antidepressants very slowly 'cos I needed, I was on antidepressants, antipsychotics and mood stabilisers. So Quetiapine, and Venlafaxine and Carbamazepine. (I was) on maximum doses of all of them as well, so like really high dose. And I need to be able to get up in the morning, so I stopped the antidepressant, 'cos I figured I could probably deal with the depression if it started... (C:121:4) So I reduced that just really slowly and nothing major happened really... (C:65:1 – C:65:6) *Participant was then able to reduce mood stabilisers and then antipsychotic medication, but then found that she had forgotten how to fall asleep naturally without medication.* (C:65:6) I was just laying in bed next to J*** (husband) going, "So how do you do this?" You know? I was just like was unconscious I didn't know the process, and that was really frustrating, I used to just like lie there going, "Come on. Sleep, sleep, sleep!"

Experienced initial increase in psychotic ‘symptoms when coming off medication

Shortly after coming off medication became paranoid and experienced increase in psychotic symptoms

(C:126:7) I started to believe that my thoughts were leaking out of my head and there were people doing brain surgery on me and I was still trying to work at this time as well, so trying to get on the tube with people like having all my thoughts felt very violating. And yeah, I had to stop working ‘cos I just couldn't go out and I also find it very hard just to make decisions, I found it hard to stay present, J*** felt as if he'd lost me, as if I wasn't there... (C:128:1) Time didn't really make any sense in that, in that period, but I think it was probably, I was only off work for maybe 2, 3 weeks. I think those kind of experiences lasted longer, maybe a couple of months, but they were most intense for that sort of 2, 3 week period.

Participant developed own coping mechanisms for increase in paranoia and psychotic symptoms following cessation of medication

(C:127:4) we got through it. And a lot of it was just hanging on in there and trying to get, yeah just trying to sort of wait it out and know that this is part of it. And got some coping strategies, like listening to music so that people would only steal the music from my head which got me back into work so I believed I was sharing Deftones with the whole the tube carriage and trying to strengthen my mind so people couldn't do kind of brain surgery on me...

Coming off medication brought a return of voices and the desire to go into psychotherapy

(C:129:4) I'd mostly not had voices while I was on the meds, I'd had some but they weren't present all the time and then they came back and it was like, yeah, I just felt unable to cope and thought, “Damn it I need therapy!”

Participant met with resistance from psychiatrist when coming off medication, which made it more difficult

Psychiatrist's anxiety provoked paranoia in participant

(C:66:1) I spent a lot of energy dealing with psychiatry and less energy dealing with myself I think sometimes... (C:67:1) They were really, *really* anxious it was like we were trying to calm them down. But that made me bad ‘cos then the voices were yelling at me and I was having this thing where she was telling me I was more likely to kill people and kill myself and that this illness wouldn't go away, just ‘cos I wasn't taking medication... (C:68:1) (laughs) They were yelling that it was right, that I was ill, that I was crazy, stupid... (C:68:8) I just got stressed and I think the (more) stressed I get, the more stressed my internal world gets. And without J***'s support I would have gone back on the meds, it just felt too much at that point.

Paranoia provoked by psychiatrist's anxiety deepened, however, this was used as evidence for why participant needed to be on medication in the first place

(C:69:3) I could feel people in my head, experimenting on me and all that stuff and of course, in retrospect, *that was psychiatry*, that was the doctors. They were, they were trying to do stuff and I felt very powerless and then that set off my beliefs again, which then reinforced their idea that I needed the medication... (C:127:1) I tried to get help from the system again, but they were like, “Take the meds or don't, you're not going to get anything else from us, so it's like if you don't take the meds we're not going to help you, there's no other option, there's no therapy or anything”. (C:69:9)

But he (*husband*) held onto the fact that this was understandable and helped me get through it. This was before therapy.

C11) Statutory mental health services are structured in a way that does not meet people's needs

The mental health system is a dumping ground and is not helpful

(C:157:19) it's like it's so stuck the whole system, it's very hard to see alternatives when you're in the middle of it... (C:158:1) it's nothing about health... It's social control really. Yeah. Dumping ground. I think it's really sad for those really good people that work in it because it's not that it's full of evil people that try and hurt them and I think if they heard the story that I've just told you, they would probably feel really bad because they're trying so hard to make things better, but they're operating in the wrong system...

Participant feels there should be alternatives to current mental health system

Treating the person as a whole, not a diagnosis, and prioritising their personal narrative would be helpful

(C:160:2) diagnosis clouds everything really. Talk about issues that people are having at the time and try and see people holistically. I hate that that's the idealised version because actually that's really human and that should be the realistic version...

(C:161:1) I think prioritising the person's narrative and understanding that that's going to change as they grow... (C:161:5) Whereas, the system at the moment acts very rigid and encourages you to have a fixed view of yourself and not change, "You are schizophrenic. You are this."

More treatment input from service users with 'lived experience' would be helpful

(C:162:1) I could add lots of things in where people with lived experience could walk along side you, and all of those beautiful things, I think that's very necessary.

Seeing person holistically requires looking beyond medical treatment

(C:162:3) And also completely ditch the whole lines approach to the mental health service, taking away where you have a diagnosis that indicates a certain treatment, you've got NICE guidelines for it... (C:162:6) this whole conveyor belt approach is just flawed, so having a more holistic approach and looking outside of medical treatment...

Without taking charge of own treatment journey participant felt they would have ended up in long-term residential care

(C:157:2) Even telling part of this story, you kind of realise that things were so stuck and people were starting to see me as a long-term severely, never-gonna-get-better – (C:157:6) it's not just my word, it's kind of what's written (*in participant's psychiatric notes*), and there's this one, a sort of discharge CPA thing that was saying I need long-term sort of residential care and they were gonna look for that.

Participant D – Individual Depiction

Now in his early forties, (D) had an initial experience of psychotherapy in a secure hospital, and then in a medium secure unit. Later, he worked with a counsellor for several years, and then after a pause, began working with another counsellor recently. (D) grew up in a violent household, in which his father regularly beat his mother, before abandoning the family when (D) was 6 years old. After attempting to leave home, and failing several times, (D) felt the only way to become independent was through committing crime, which he hoped would lead to prison and then being rehoused. He served a prison sentence for robbery, but became increasingly paranoid and violent, and was sectioned in a psychiatric hospital. He was treated there with anti psychotic medication, but did not have an opportunity to talk about what he was experiencing.

After being released from psychiatric hospital, (D) returned to the community, but came off antipsychotic medication to be more alert and better able to deal with a street vendetta that his brother had become embroiled in. After having his life threatened, (D) developed a delusion about a fellow service user at a day centre, whom he believed to be the bisexual gangster, Ronnie Kray. After becoming convinced that the service user was planting bugging devices in his flat, (D) stabbed him to death. Following the killing, (D) was sectioned in a secure hospital, and this is where he first encountered psychotherapy with a clinical psychologist. Later, when discharged to a medium secure hospital, (D) worked with another clinical psychologist. (D) felt both experiences were an important part of his road to recovery and he took all the therapy he could get at this time.

This therapy work helped (D) to understand that he was traumatised, but not mad. With this realisation he began to see schizophrenia as a way of escaping the life he was born into, and that these traumatic experiences expressed themselves in symptoms. Being able to explore freely this relationship in psychotherapy helped (D) to understand himself and how he had been affected by the people around him. With this understanding then came a feeling of greater self-control. For example, (D) had a complex relationship with his mother, who herself had a relationship with a God voice. (D) was beaten by his mother for being darker than his siblings, and for displaying ungodly thoughts, or thoughts of a sexual nature. Growing up he felt timid by nature and confused about his sexual identity, but learned to mask these fears with violence. In working through these issues during psychotherapy in hospital and a secure unit, and in the counselling that followed, (D) feels he has been able to develop a greater sense of what is real, or what is outlandish thinking. He also feels that this therapy work helped him to reduce his feelings of anxiety to such a degree that he no longer hears voices, or experiences extreme paranoia. (D) feels that medication has also helped him with these issues, although he would like to come off medication all together in order to continue his psychological journey, but is wary of potential consequences.

(D) now has his own family. He is active within HVN, and attends peer groups and events. He would like to help others with experiences similar to his and has begun a counselling training toward this end. (D) feels this training is helping him with his continued psychological development, and that his paranoid schizophrenia diagnosis is no longer appropriate.

D1) Experienced a traumatic childhood

Grew up in deprived circumstances

Didn't have enough clothes or food when growing up

(D:19:1) mother was saving up all child benefit money to spend for things for herself. We were always hungry, always needed clothes, which we didn't never have enough...

Brother smashed furniture because not enough to eat at home, so furniture was taken away

(D:19:5) my eldest brother knew there was a problem and made everything worse by smashing everything in sight because he couldn't get enough to eat, or whatever. And they've taken all the furniture out and we've all suffered, we all suffered even more because of him.

Family environment was violent and abusive

Abuse was taken as normal at home, but when visited friends, could see that their families weren't like that

(D:142:1) my father beat the hell out of my mother - I see my brothers fighting with each other all the time. I see my younger brother getting violent with every Tom Dick or Harry on the street that he got into an argument with. (D:13:5) (I was) constantly seeing abuse around me, and I was taking that as being a normal thing, even though at the back of my mind I knew it wasn't because other families wasn't like that and I had the experience of other families – not living amongst them, but you know, going to their houses and seeing the way they interact and whatnot.

Felt like family were taking him over and wanted to get out at earliest possible opportunity

(D:13:1) growing up, I had a lot of problems in my family. I didn't like living in my family. I wanted to get the nearest opportunity to get out, but then I kept on getting dragged back in because of my caring nature... (D:13:4) I didn't know who I was, I was constantly being used... (D:130:1) It felt like, dunno, just like they were taking over me, that's what it felt like, they was just taking over me. I couldn't make choices myself.

Father was violent and abusive

Father was sexually promiscuous, violent toward women, and left home when participant was 5 or 6 years old

(D:191:2) My father was a tart. He liked to have as many women as he could get, and he would beat down on these women just so he could get some more. (D:191:1) He left when I was about 5 or 6. Something like that. He was never really around anyway.

Father was sexually abusive toward mother in front of participant

(D:196:1) He used to come home and entice my mother into bed by putting his hand up her skirt. My father. In front of us. (D:197:1) She would say no to his advances, and he would drag her upstairs.

Father used to beat up mother to get money from her, but mother would never press charges

(D:27:3) even when my father used to beat her up for her money, she would never press charges.

Mother discriminated against participant because he was darker skinned than his brothers

Unlike brothers, participant didn't receive gifts because he was darker skinned, and felt segregated from the rest of the family

(D:14:4) I'm seeing the way my mother buys something nice while it's for my brothers, and my little brother gets a little go-cart with a blackboard and whatnot growing up, I don't get no anything. (D:14:7) it's because I'm darker than the rest of my brothers. So she's like segregating me from the family...

Participant was beaten by his mother for having darker skin and because she believed he was talking to God

(D:142:3) I experienced my mother beating me because I'm darker than the rest of my brothers.

Wanted to get close to mother but felt she kept pushing him away

(D:116:11) I remember the early days I was trying to get as close to my mother as possible - obviously being a child, that's my mother. And she was pushing me away, pushing me away.

Mother heard voices

Mother had a relationship with a God voice

(D:16:9) I was brought into the world by a mentally ill mother and an abusive father.

(D:116:8) (She had) this very deep relationship with a voice or voices she was experiencing. Which kind of like, I gather, the way she was talking to them, they came from God. In her mind. And that was my earliest experiences.

Mother beat participant for talking to God in the wrong way

(D:14:8) I remember like growing up with her and I'm playing at her feet and she hits me over my back with a broomstick and says, "Don't talk to God like that!" What do I know about God at the age of 7? It's abuse! (D:145:1) She didn't explain it to me she just acted it out in front of me.

Although frightened by mother hearing voices, was jealous of her voices because they had a communication with her that he didn't

(D:147:1) It was ... frightening in one aspect, saddening in another aspect, watching her go down that road. And I was very jealous of the voices 'cos they had a communication with her and I didn't.

Feels his sexual growth was stunted by witnessing his parents having sex when he was 4

(D:187:1) I think what explained my stunted sexual growth, mentally, was the fact that I saw my mother and my father having sex one time. Crept upstairs and realised they was having sex. Don't know how I realised it, but it dawned on me. And after that - not very long after that - I started experiencing sexual feelings myself.

Aged 6, beaten by mother for becoming sexually aroused when she bathed him

(D:187:4) My mother would wash me down and I didn't want that because I was feeling the sexual feelings, and obviously, she's washing me intimately, I'm getting aroused. And she beat me for that, see what I'm saying? And I couldn't talk to her about it, and she wouldn't have listened anyway, but I got beaten for that. So it all felt like to be sexual was wrong, which could explain the reason why I was so sexually confused.

After father left home, had to share a bed with mother, which felt confusing, and provoked aggressive feelings

(D:203:3) *(After father left, had to share mother's bed because there was no room elsewhere)* at the time I'm thinking that maybe she wanted to sleep with me, see what I'm saying? Which made me even more aggressive, 'cos I don't wanna sleep with my mother.

Friends not allowed in the home, and felt mother wanted him to live like the local priest who she was in love with

(D:191:4) girls weren't allowed in the house, let alone male friends. She allowed nobody in the house whatsoever, so I felt like she wanted me to live like her local priest who she was in love with. And he was a priest, you know a Catholic priest, and that's not something that I wanted.

Bullied at school and by friends

Even though bullied at school, it felt like a release from abusive home life

(D:18:1) School was a release for me really. Even though eventually I went on to get a bit bullied... (D:18:3) And I was doing well. Because I didn't have no TV or music indoors, the 'O' Levels gave me a space to express myself, just by doing my schoolwork.

Abused by friends because was used to abusive relationships, and this pushed participant to become violent

(D:142:7) If it wasn't so bad what happened at home, eventually it started happening in my relationships with my so-called mates as well. They were getting violent with me, spat in my face, getting kicked in the face for kicks. Getting punched on regular... I was getting abused, and that's what really pushed me to be violent.

(D:143:1) I think I was just attracted to them relationships, 'cos that's what I was always used to.

D2) Confusion in adolescence and early adulthood

Had no self esteem and wanted to be someone else

Never felt good enough and was getting into trouble frequently

(D:45:1) When I was growing up, I always felt that whatever I did would never be good enough and I was putting myself in trouble and not being able to get out of it by using my own strengths, getting out if myself.

Had no self-confidence and would constantly change who he wanted to be (D:149:1) I felt very, what's the word now, unworthy of anything. I was always trying to be like everybody else. I could change who I wanted to be like 3, 4, 5 times a day. Because of

people I'm meeting in my life, do you see what I'm saying? I didn't have no self-confidence, no self-esteem, and I thought I was unworthy...

Felt confused about sexual identity

Exposure to pornography was confusing and led to hospitalisation

(D:158:1) (What led to first hospitalisation was) I went to a pornography shop, saw some pornography that was, I didn't know how to handle it. I went home and got sexual with myself, didn't know how to handle that... It's very vague and very unsure, but I think that was the start of what pushed me.

Advances of gay man contributed to feelings of violent paranoia and hallucinations about the Kray brother gangsters

(D:158:4) I was getting the attentions of a young, obviously outwardly gay man at the time. (D:158:7) And tried to say, "Look I'm not interested." But he was still coming on to me. And I didn't know how to handle that, so I kind of like tried to, nearly got a bit violent with him. (D:159:1) And then I started getting the hallucinations about the Krays, and then that all added to that as well.

D3) Attempted to move away from family, but got drawn back in

Moved into cousin's house and got involved in criminal activities and taking drugs

Moved away from home, but got involved with criminals and taking drugs

(D:124:1) I just went out there, talked to my cousin and he got me a place to live, I moved my stuff down to there, I got involved with criminals. Started thieving, smoking a lot of drugs - not compared to them - but I was smoking what I thought I could handle.

Got evicted, moved back to home town and it was all downhill from there

(D:127:3) I got evicted along with the rest of them and ended up back in, in C**** Town where I come from. And it was all downhill from there...

After returning home, assaulted mother

Beat up mother because thought that getting her away from the home would make things better for himself and his brothers

(D:127:6) I said to myself, "Look, I've got to get back on my feet, I wanna do good things, let me try and see if I can get by to help out my family, to help out myself." (D:199:1) she wouldn't let me live my life growing up in that household, and I didn't have nowhere else to go. So, that's why I kind of beat her up, 'cos I was getting more and more confused by it all. Getting more and more aggressive by it all. (D:25:2) (It) was a community response to the deprivation we was living in. I felt; my reasoning behind it – even though it was a bit crazy – was that, if I could kick out my mother onto the street, we could have something better...

Accused mother of making him live like a priest and was laughed at, so reacted violently

(D:203:6) I said to her just before I beat her up, that, "You want me to live like a priest and you're forcing me to live like a priest, so I'm gonna force you to live like me, how I want to live. So if you don't actually leave my stuff alone, stop playing

with my stuff, I'm gonna beat the hell out of you.” And that's what I did, ‘cos obviously she's not in control of herself, she just went and started laughing about it which really got my goat up... (D:204:1) it's something that I'm ashamed of but at the time I had to do it.

After assault on mother, was released without charge into care of elder brother, but became paranoid that brother wanted to sexually abuse him

(D:27:6) I just didn't feel right there. (D:28:1) I thought he was going to take advantage of me. (D:127:12) I got paranoid, really paranoid in my brother's house, I thought he was out to sexually abuse me...

Went to prison after committing 3 robberies

Saw prison as a way of escaping family

(D:28:3) my younger brother went to prison. And he got a place by himself. So I figured that if I can't be good to get what I want, I'll be bad. So eventually, I went and robbed 3 shops, all in a row on the same night. (D:28:8) that was the start of me separating myself from my family.

Couldn't cope in prison, became paranoid and was sectioned

(D:28:9) the only problem that was, I did go to prison, I was very paranoid, I couldn't cope in prison, I did end up doing some really crazy stuff that got me sectioned.

Sent to hospital and on road to recovery, but was still in contact with family, which didn't help

(D:34:1) Eventually they said that it wasn't good for me to go back to prison, so they sent me to hospital in C****. I was on the road to recovery, but I was still in contact with my family, which didn't help. (D:34:4) I was still mixed up with my family, and I was still part of the family.

D4) Using recreational drugs compounded problems

Realised that cannabis provoked psychotic episodes

Experienced a psychotic episode after smoking cannabis buckets

(D:124:4) Had a psychotic episode on one of the nights, extremely, it was terrifying, terrifying, because I was smoking (*cannabis*) buckets. (D:125:8) I did that and I got a very bad psychotic episode. I ran out of there and I had to just hide. (D:125:6) They was looking for me and eventually they found me hiding behind some dustbins.

In hospital, advised to stop smoking cannabis, and realised that it wasn't doing him any good

(D:131:3) they said look I shouldn't be smoking it. I went through a period where I didn't have none. And I just realised that basically I, eventually I realised that it wasn't doing me no good.

Tried cannabis again after leaving hospital and realised that it made things worse, so never took it again

(D:131:3) I stopped taking it until I got out of hospital and I was in a hostel. And I did go back to drugs as an experiential thing, to find out if it was really that that was causing me to be ill. (D:1:32:1) I realised that smoking it, I realised that I'm going

down, I'm going down. This is happening again. And I stopped it and I never looked back.

D5) Learned to mask fear with violence, which fuelled paranoid delusions

Had to become violent to survive

Was scared, and felt that being timid would get him killed, so became aggressive to survive

(D:39:1) I was scared: very scared. Very scared. And when I was in hospital...

(D:39:2) I started to get pretty fierce, and pretty fearless... (D:39:3) I didn't want to go back to being timid. I went from two extremes: being very timid, to being very, very aggressive, and I knew that if I was very timid around these people, I'm gonna get killed. And that was no delusion either. I don't know why I couldn't tell people about it, I just thought I just couldn't.

In a life of extremes, had to live by extremes

(D:114:1) maybe it's because my life's always been about extremes. I was brought up in extremes, so I've had to live my life by extremes.

Frightened by feeling of losing control of self and everything around him, and felt in constant danger

(D:206:1) (it's) frightening. Knowing that you've got no control over your life.

Everybody needs to feel some kind of control and I think that I was losing mine at a steady pace. Everything. Not just my own control, but control over everything around me. See what I'm saying? And it was all looking at me. And it seemed like I was always in a dangerous situation. That's how it felt.

Couldn't talk about paranoia because didn't have the right vocabulary at the time

(D:44:1) I didn't have the vocabulary to talk about it. I was a very simple person at the time. I remember when I eventually ended up in R****, and I had an IQ test and they said I was below average and they said it's understandable because of my psychosis.

Became increasing paranoid after being targeted in a street vendetta

Came off medication to defend self after beating up a man who assaulted his younger brother

(D:34:5) I took myself off the medication, especially for the fact that I was in a vendetta with individuals that was on the street 'cos they beat up my younger brother.

(D:36:1) he was the best in my eyes, and when I see the state he left my brother in, it kind of like hit- I just didn't know what to do about it. So I just went and beat the hell out of him. (D:38:1) the next time that I was with my brother, he come running at me with a car iron... (D:38:4) He put out my leg for a good 2 weeks. That's when I knew this was serious.

After being targeted in street vendetta, became paranoid and went into a shell

(D:42:1) All I remember was I would listen to music in a chair and I was just rocking backwards and forwards, because that's what I felt to do. I can't remember what my

delusions were at the time, but I was definitely paranoid. Very paranoid. And it was getting worse and worse.

Paranoia felt like an intense anxiety and wasn't able to talk about it

(D:43:1) It was just frightening. It's an intense... Cos it's mixed with an intense form of anxiety. I can remember some of it, but not all of it because I'm not that person no more. But I still remember some of it. But when you live it, you live it. You won't talk about it either, you just live it.

After discharge from hospital, developed paranoid fantasy about fellow service user and murdered him

Afraid of service user at day centre, and became convinced that he was the bisexual gangster, Ronnie Kray

(D:47:1) when I got released from the hospital, I was going to a day centre and there was one man there that I just took a fear from, because I was really paranoid, and I was really delusional. And they was all gathered round him and calling him by name. And I thought that name was someone that I- I had a dream about one of these 60s gangsters and his crew and all that, and I thought that was him! (D:47:7) And I kind of thought that *he* had a vendetta against me...

When service user turned participant's music off without asking, felt disrespected, ridiculed and afraid, and wasn't able to rationalise that it wasn't personal

(D:50:1) I had a friend in there, one of my only friends in there, and he kind of like, he was a very kind of timid guy, and I liked him, he seemed kind of honest. I really liked the guy. And we were playing music, and the guy come over – the same one that I killed – and just turned off his music without even saying “could you turn that down please?” and getting a response. He just come and turned it off, and I took offence to that. But I was scared of him, so I just didn't say anything. (D:51:1) It was like a total lack of respect for me as a person, mixed with ridiculing me. Instead of me just thinking that person is not well – like now if I come across that now, I'd think that “you're strange” and put it out of my mind and get on with my life. But at the time it made sense to me and that was what triggered me off.

Became convinced that bugging devices were being left in his flat by service user who he had developed paranoid fantasy about, so killed him

(D:130:5) When I was in my flat, I was imagining things, people was leaving stuff in my house, they left bugging devices and what not. Which was getting me more and more paranoid - I was getting more and more paranoid I should say and I just exploded. (D:130:8) I thought that everything that I was experiencing in my flat was related to (*service user he was afraid of*). (D:51:7) I'd had enough. No one knew it, but I was always walking around with a dagger in my pocket in my jeans. And I though, “Right. It's either you or me.” (D:130:9) And I went back and killed him.

At time of killing a man, had developed murderous thoughts about anyone he felt treated him badly, and thought he could have become a serial killer

(D:165:3) I could have been a serial killer. 'Cos my head was that messed up, I had murderous thoughts towards people that I considered got one over on me. That treated me that badly that I couldn't get over it and I wanted to do them some serious harm. And it just so happens that I did it to one person after I lost complete control of myself.

Felt like everything had gone wrong in his life, and that by killing man who he had a developed paranoid idea about, he would spend life in prison and be able to start afresh when released aged 60

(D:167:1) I'd just thought I'd had enough. My life was turning to shit. That's the only way I can describe it. There was nothing left, see what I'm saying. (D:166:1) I thought that everything that I was doing was going wrong and I said to myself, "Do you know what yeah, we'll go and do this and start all over again." (D:166:5) I thought that I'd be convicted of murder and probably serve 30 years in hospital which I would have - not in hospital - in prison, and I'd be released about the age of 60 and just start afresh.

D6) Experienced voices in the past, but no longer hears them

Heard the voices of two sisters when he was in prison

Heard the voices of two sisters that he knew and was completely immersed in them at one point

(D:64:1) The voices come in that form – two girls that I knew. One of them was a girl that I... They were two sisters, one was about 3 years older than the other. (D:71:1) I'd hear them quite a lot, yeah. At one time I was completely immersed in them.

Older sister voices would make participant prove he loved her by hitting people, while the younger voice would try and dissuade him

(D:70:1) The older one was making me hit people, and the younger one was telling me not to do it. And I had them voices all the time. (D:73:1) The older one was saying, 'If you love me you'll hit someone.' So I'd go and hit someone.

Was often violent after hearing voices, so was restrained and put in isolation, and then finally sectioned

(D:75:1) I'd be restrained, thrown into the block, where I'd talk to them even more – to the voices. Come out and do the same thing again. Eventually they got fed up with me and sectioned me. And that's when I ended up in the hospital in C*****.

There is a strong relationship between voices and fear

When first heard voices, was terrified of them, but because he doesn't fear them now, feels it's unlikely they'll come back

(D:180:1) When I first heard the voices, I was petrified of them. But like now I'm not frightened of them, so they - I don't know if I can see them coming back (*laughs*) especially taking control of my life anyway.

When participant accepted the voices and stopped feeling frightened of them, they went away

(D:176:1) I stopped reacted to them. They petered out, and eventually they just went. Simple as that. Well, it started off I stopped becoming frightened of them, stopped becoming frightened of the experience, then I ignored them, then they went away. (D:177:1) I accepted that I was having them. I was in a better place.

Because he's not frightened of voices anymore, participant sometimes hears them like a distant whisper, or a memory

(D:180:1) Sometimes I can experience them - like a little whisper, where I'm remembering the voices and how they had a big impact on my life. But then, yeah, just, I remember it. (D:181:1) it's become more distant, 'cos I'm not frightened of it.

D7) Road to recovery begun after being sectioned in high security hospital

Murder attracted press attention, but felt safe in hospital and protected by the staff

(D:52:1) I was interviewed by a Sunday paper and they rubbished me even more, but then at least I was safe there. I felt safe there because I had all these staff around me and if anyone wanted to hurt me they had to get through the staff first. (D:178:3) I knew that I was also in a better place when I was in hospital rather than in prison or in the community.

Wanted to stop acting and reveal the frightened, timid person he felt he really was, but still felt he had to become aggressive when defending himself

(D:55:6) when I got attacked in R***** I defended myself and went over the top. I felt frightened, that's the person I was. Cos I didn't want to be acting anymore at something that I wasn't. I wanted to let everybody know the real me. And that was like being a frightened child even though I was a full-grown adult. That's what I was.

Realised no one was going to help him but himself, which was the start of the road to recovery

(D:45:4) when I went to R*****. Then I realised I put myself there and it's up to me to get myself out of there, because no one else is going to help me. And that was the end of the road – I travelled back up the road to recovery. And I travelled from the bottom to where I am now.

At the time, felt that he could only access treatment by committing crimes

(D:111:8) the worse thing about it is that I could only get their service by committing crimes. If I did not go down the route that I took, I wouldn't be able to get them services.

D8) The schizophrenia diagnosis defines how people see you

Still has a paranoid schizophrenia diagnosis, despite feeling he's outgrown it

Feels he has outgrown diagnosis of paranoid schizophrenia, which he has had for 20 years

(D:3:1) I've still got the diagnosis of paranoid schizophrenia. I wouldn't describe myself a *paranoid schizophrenic* though. That was a long time ago and I've progressed so far that I think I've outgrew it.

Wants to change diagnosis of paranoid schizophrenia so that he can come off medication

(D:3:5) I'm trying to change their minds in that I actually want to eventually come off medication completely. I think I've approached my treatment... and recovered to a point that I think I could come off and make a successful go of it without medication.

People are afraid of the schizophrenia diagnosis and its hard to escape the condemnation that comes with it

People are afraid of the schizophrenia label because they're afraid of the unknown

(D:7:1) (It's because) everybody's afraid of the unknown. Most people are.

Schizophrenia label frightens people, because they think you'll be erratic or violent

(D:5:3) When you're labelled as a schizophrenic, people get a bit wary. In the least they get wary of you. In the extreme they're frightened of you and they don't want nothing to do with you. And you might not have done nothing to them. (D:6:1) The fear is that you're going to be violent, that you're going to do something erratic, or something that's in the extreme that will do something detrimental to that person.

Media portrayals of mental health problems are condemning

(D:7:1) the way that the media portrays people who've got mental ill- mental health problems it could be schizophrenia, it could be bi-polar, once they've said it, you're mentally ill, that's it, they condemn you.

D9) Medication has been useful but has also had severe side effects

Medication has been helpful

Was prepared to deal with the side effects of medication because wanted to try anything that might help with anxiety and depression

(D:56:1) I talked to the psychiatrist and he said he was going to put me on medication, and I was quite grateful for it at the time. I just wanted to try anything to take away the anxiety and depression. And when I did get on the medication I realised that I've got to deal with it. Even with the Depixol with the tranquillizing effects, I knew I still had to deal with it because it was still there.

Had relief from voices when started on antipsychotic medication, although can't explain why

(D:178:1) medication had a big impact on that, I think medication did. I'm not sure, I can't explain it... (D:70:2) I had some relief from it (*hearing the voices of two sisters*) when they put me on medication.

Feels freer with current antipsychotic medication, Modecate, than with previous medication

(D:12:1) I realised I was a lot more freer, I realised I could feel my emotions, I wasn't so drowsy, even though I was depressed, so I was sleeping a lot anyway, but I wasn't so drowsy, I could feel myself, and because I could feel myself, I could get to know myself.

At back of his mind, felt that medication was helpful for stability

(D:139:1) I was coping, but then at the back of my mind basically I needed medication. I needed the intervention of a psychiatrist and medication. I was still a little bit unstable, even though I think the medication helped at that time.

Wants to come off medication, but is wary of doing so because became unwell when had tried it years before

Has no problems with medication now, other than feeling that he doesn't need to take it any more

(D:10:1) I've been on Modecate depot since 1996, I think it was. 50 milligrammes of Modecate or Fluphenazine Decinate I think they call it the official term. I've been taking that since 1996 and I ain't got a problem with it. Except for that fact that I don't need it now, so why should I take it?

Despite feeling that medication has not been biggest contributing factor to recovery, his training as a counsellor has made him question his desire to come off medication

(D:170:4) It's actually strengthened the fact that, I wouldn't argue for the fact that even though I don't think that medication has been the biggest contributing factor towards my healing, but I wouldn't argue to come off of it.

In the past, came off medication to feel more alert and deal with the threat of a street vendetta, but became more aggressive and unwell, and is wary that might happen again

(D:39:7) (I came off medication) before and ended up in a world of excrement. I took myself off the medication and went back to being as nutty as ever. (D:173:1) I just went straight back to the way I was. I started becoming more argumentative. I had the confidence behind it as well. So I become more aggressive. (D:1:172:1) This time I wouldn't do that, I've learned that lesson. And like even though I feel that I can get on well without medication, I would not argue the point.

Learned to conceal what he was experiencing to avoid medication being increased

Was encouraged to be open about feelings of paranoia by psychiatric nurse, but then found his medication was increased without consultation, so decided not to be open again and to try and cope with the feelings by himself

(D:57:1) when I first ended up in R*****, there was a staff nurse that said to me, "If ever you feel paranoid" – which he didn't know I was feeling paranoid all the time – "Whenever you feel paranoid, come and talk to me, and I'll help you." So I went and talked to him and they increased my medication. It's not what I wanted. I wanted someone to talk to. So, after that, I decided that I'm just going to cope. I'm not going to tell them that I feel paranoid, I'm going to cope with it. And that's what I did.

After medication was increased, felt even more paranoid

(D:59:1) I felt the same, even worse. (D:60:1) I just felt even more paranoid.

Some antipsychotic medication had severe side effects

Clopixol antipsychotic medication had severe side effects which were reduced by taking Procyclidine, but inability to produce sperm remained

(D:62:1) I was getting muscle stiffness. What was it? My seed had dried up. What else? Also I slowed down a lot, I felt very slow. My mouth- my tongue was sticking

out me mouth as well. And they put me on Procyclidine, that took away all the other side effects, apart from the fact that my seed had dried up, and that continued; I couldn't produce any sperm.

Felt so pleased to be on a medication that didn't have such adverse side effects that decided to behave himself in order to not be put on worse medication again

(D:62:9) I was really pleased and I wasn't going to do nothing to mess it up, because if I did, they would have tried me on different other drugs. So I behaved myself, and to this day, I'm still on it.

Learned to keep his mouth shut and bear treatment

(D:61:1) I realised that if I carry on telling them I feel paranoid the way I do feel, I'm going to be more medicated. And the medication's not doing nothing for me, so I'm not winning. So, that's when I just learned to keep my mouth shut and bear it. That's when I learned how to cope...

D10) Where psychotherapy has been unhelpful

Psychiatrist used to make participant do things he didn't want to do, such as suggesting that he make up with abusive father

(D:77:1) I was talking to the doctor... This crazy doctor (*laughs*). I don't know how he become a psychiatrist, but he wasn't very good anyway, and used to make me do things that I didn't want to do. (D:78:1) For example, making up with my father. I told him my father's not a nice person, I shouldn't be around him. He said, 'maybe you should make up with him, make sure you're winning the arguments', and things like that. So I did that and it wasn't a very good idea. We soon went our separate ways again... (D:79:1) He thought it would be helpful. I don't know what his reason was at the time. It was a crock of shit and he was an idiot.

D11) Where psychotherapy has been helpful

Psychotherapy has been an important part of recovery

Participant took all the psychotherapy he could find and got better and better

(D:76:1) I just got better and better. I took all the therapy I could find.

Psychotherapy in hospital led to road to recovery

(D:130:11) When I ended up in hospital I got the psychotherapy. That's when I got on the road down to recovery.

Psychotherapy helps to talk about difficult material

Talking therapies are helpful when there's issues that can't be talked about with anyone else

(D:106:2) I do use talking therapies because I do find them very helpful. And I do use them when I need to. (D:107:1) Just for the fact that I can offload on somebody – tell someone (something) that I can't tell most people. Not even my wife. If I can't tell my wife then I know that I've got to take it to talking therapy.

When participant feels he could do better with his life, but doesn't know how, psychotherapy is useful

(D:108:1) When I feel that I could do better, but I don't know how to do better, I take it to talking therapies, and we'll talk about it. And then maybe I'll come to terms with the way I'm living my life, and then maybe I'll do that bit extra to get back on track.

Psychotherapy helps you find the right answers without putting words into your mouth

(D:109:1) they kind of help you find your own answer. They don't put words into your mouth, they just get you thinking about stuff, maybe from a different perspective from what you're thinking. And then you come up with your own answers. It's as easy as that. You kind of need them to be able to do it, which is the kind of like – not crazy thing about it - it's not as simple as you think. Cos you do need someone to bring out the right questions and to bring out the right answers for you.

Psychotherapy helped participant reveal what he felt to be his true self, which was timid, and was able to work forwards from that

(D:116:1) I had to accept that I wasn't as tough as what I thought I was. I thought I could handle anything, which is the problem why I ended up going through therapy in the first place, and having all these mental health experiences.

(D:55:1) I felt *really* timid, and I worked myself from that to the person that I am today. From instead of being aggressive and working backwards, I worked from being timid and working forwards.

In secure hospital there was a space to be open about what he was thinking

Couldn't see relevance of psychotherapy at the time, but it felt like a breath of fresh air to be able to get into the open things that were happening in his life

(D:82:1) At the time I couldn't see the relevance of it. I think anyway, but then also at the time, it was like a breath of fresh air because I was able to talk about stuff that was happening in my life. I was able to get it all out in the open. To tell someone about it. It gave me that little bit extra, that I kind of liked. And I took it for what it was and I opened up to it with both hands open. And yeah, it was good.

With psychologist, was able to talk about personal issues, interactions with people, and about problems in the more immediate sense

(D:81:1) I can't remember a lot of it. A lot of it was to do with what I was already working on, like um... my interactions with people, and things like that. (D:81:4) there was one particular stuff that we talked about which is too personal for me to talk about. See what I'm saying? But most of the time it was immediate stuff.

Psychotherapy helped to reflect on, and make sense of, complex relationships, including family relationships

Was able to talk about relationships past and present, as well as intimate material

(D:82:6) I remember like, I was able to talk about intimate stuff. And my relationships, anything that affected me at the time, or in the past, and talking about everything from my family to my relationships within the hospital. I think we talked about my index offence as well.

Able to accept family because he was able to become his own person and view them from the outside with different eyes

(D:82:22) I started to look at my family differently. I started to look at my family like - how do I describe it? I'm part of my family, but I'm looking at it with different eyes. I'm looking in from outside. You see what I'm saying? I'm still part of my family, but something strange happened where I don't feel part of my family, I started to feel more *myself*. I think that's the best way to describe it. And I just started building on that.

Began to understand difficult relationship with mother and how this had affected him

Through Roman Catholicism, mother instilled feeling that all thoughts to do with sex, or swearing meant he was a bad person, which led to him thinking he was crazy

(D:95:1) Growing up, my mother took me to a Roman Catholic church and, the way she treated me, I thought I was a bad person because I had certain thoughts. Which were maybe swearing, thinking swear words, or thinking dirty when it comes to sex, whatever. And I thought, this is all bad things. And eventually, it led on to me thinking that I was crazy.

Mother bottled things up, which contributed to her hearing voices, and participant feels he learned a similar process from her

(D:116:4) I was taught by my mother to deal with stuff, 'cos obviously when you're growing up they teach you a lot of the early experiences, and a lot of them experiences were negative because she was the kind of person that, she kind of like bottled in everything. That's what I think she went through anyway, which led to her having this kind of, this very deep relationship with a voice or voices she was experiencing. Which kind of like, I gather, the way she was talking to them, they came from God. In her mind. And that was my earliest experiences. And I did the same thing, I kind of like bottled up everything.

Psychotherapy helped participant realise he wasn't mad, which led to a breakthrough in his recovery

Felt better at close of work with first therapist in high secure hospital, but still feared he was as mad as he thought other people might think him to be

(D:82:9) eventually, it kind of like petered off, and I felt better and I felt relieved. But I still had the niggling thought that maybe I was as mad as what everyone thought I was.

Second psychologist in medium secure unit said that her thinking was similar to his, which made participant realise he was traumatised, rather than mad

(D:82:12) for years, I was troubled by my thoughts – for *years*. (D:82:16) he asked me, how do I feel about this and that, and which ways do I think – what am I thinking when I go through this and that. I can't remember exactly what it was at the time. And I told her, and she said, 'you know what? That's what I go through.' (D:135:5) She told me that what I was experiencing was actually quite normal. And maybe it was a bit extreme, but it was normal considering my situation and the things that I'd been through. (D:82:19) So I realised that I wasn't mad. I was *traumatised*, but I wasn't mad.

Although he didn't have a deep understanding of himself at the time, realising he wasn't mad led to a breakthrough, which helped him regain control of himself (D:135:1) even though it wasn't a deep understanding of myself at the time, but there was definitely a big breakthrough in that the psychologist I was seeing at the time, I can't remember the woman's name. (D:135:7) And that's when I realised that basically I'm not a raving lunatic after all, and I can have control over myself.

Participant realised that all thoughts had previously felt like madness and enemies

Thoughts used to feel like enemies
(D:96:1- D:97:1) (*Thoughts felt like enemies*).

Participant felt he was going mad because he *thought* he was going mad and was losing control because his thoughts seemed crazy
(D:93:1) for years I thought I was going mad. I *was* going mad because I *thought* I was going mad. I was losing my control over myself more and more, because I always thought my thoughts were crazy thoughts, when they wasn't.

Wishing thoughts weren't his own, and detesting himself, led to wanting to be other people, even someone he'd only met for 20 minutes
(D:98:1) that's what led me to want to be like other people as well. I was definitely hating myself I detested myself, and I was always trying to be like someone different. I could meet someone for like twenty minutes and want to be like that person.

Previously the act of thinking at all had felt like madness, which in turn had felt like madness because he realised that *he was* his thoughts, and realised this was the effect that his mother had on him
(D:94:4) Every thought I had I thought was crazy, I shouldn't be thinking this. I should be just.... It's kind of crazy, because these are things that make me, *me*. But I would not accept them. And I think that was because of the effect of my mother on me.

Thinking about how to react to conflict in particular felt crazy
(D:136:2) I think a lot of it was to do with people like around me. Like when I was kind of like... getting into confrontation with people, it was running around, about in my mind, getting, trying to sort it out, what was my next move. I always thought that was craziness. I didn't realise that that was quite normal.

More able now to understand when a thought sounds outlandish or crazy
(D:163:1) Now I'm pretty much confident enough to say, "Look, that sounds kind of crazy, too outlandish, I never wanna go there." But at the time I was experiencing a lot of stuff.

Realising he wasn't mad helped reduce anxiety, helped him feel more certain of himself, and more able to take control of his life

Started to calm down after revelation that he wasn't mad
(D:93:3) when I got the revelation that I wasn't actually crazy, I started to calm down. I felt more at ease with myself.

In breakthrough, felt more certain about himself and was more able to take control of his life

(D:139:1) I just started to cope a bit more. (D:139:4) I started to take full control for my life. (D:139:4) Because it was all getting confirmed to me what I was doing was the correct thing for me. It was the right thing to do, whereas before I was thinking, it was all very vague and... and I thought, and I was very unsure about if what I was doing was the right thing – “Should I be a little bit more aggressive to allow me to deal with my family members”...

By feeling the predicaments that he had placed himself in, he was able to address, and take responsibility for, his issues

(D:160:1) the psychiatrist swears that's the medication, but I don't think so. I think that addressing my issues definitely helped me to take responsibility for my issues. See what I'm saying? To feel the predicaments that I put myself in and that gave me a sense of control. Positive control. (D:82:20) from then I just went from strength to strength, and I realised that I could cope with even more. So I took on even more responsibility...

Exploring issues about sexuality that had fed into paranoia helped him to understand why he killed a man

Initially had psychotherapy to deal with aggression and paranoia, rather than voices
(D:179:1) when I went to R*****, the problem wasn't voices, it was paranoia and aggression due to the paranoia. It wasn't a problem with voices.

With psychologist, was able to speak of his fears about his sexuality and how these fed into the confusion that led to him killing a man

(D:133:1) I told him that... the reasons why I killed my victim because I didn't want to turn gay. And that's why I killed my victim. I suppose I was very confused at the time. I didn't know who I was, so I was confused about a lot of things, especially about my sexuality. (D:134:1) I started talking a bit about it, about how I felt towards my victim, 'cos I thought he was Ronnie Kray, who was a well-known homosexual man. And... I can't remember exactly what I was saying to the psychologist about it, but it was kind of resolved but then it wasn't, not in my mind.

Process of psychotherapy helped participant to learn from his experiences, and regrets killing a man

(D:159:5) I've learned from that experience. I wish that I didn't kill somebody, but it taught me something. Which is... Maybe I should have died as well. But I'm glad, very much glad to be alive.

Recently has worked with a counsellor to continue addressing sexual issues

Able to talk about complex sexual issues in recent psychotherapy

(D:151:1) I was able to talk about it (*issues with sexual identity*). All of my aspects, even the sexual part. Eventually I did that about 2 years ago, and come to terms with that.

Started working with counsellor because felt unhappy about being addicted to pornography

(D:154:1) Because I was very unhappy. I thought that I had no control over - 'cos I was watching a lot of porn at the time - and I thought I had no control over it. And it

was taking over my life. I knew that it's not helping me but I couldn't stop it. Even today I watch porn. But I've got more control over it and I knew- I'm working towards cutting it out completely, 'cos it's very unhelpful - to me anyway. Some people get on fine with it, can use it recreationally. But me, I'm addicted to it like I was with cigarettes.

Counsellor helped with fear that watching pornography meant that he wasn't normal, and in normalising it, began to feel ashamed

(D:156:1) It just got me to see that basically what I was doing was actually normal, even if I didn't like it, but I always thought, I was abnormal because of it. It all stemmed from the fact that I didn't think I was worthy so... (D:157:1) eventually, towards the end of the therapy, I come to the conclusion that basically it was normal. And that even though... I started feeling ashamed myself. Put it that way.

D12) Schizophrenia has a meaning and context

Participant feels that his personality was retarded by his family and the mentally confined space he was born into, and schizophrenia was a way of escaping it

(D:16:1) I think the whole problem, the reason why I got the diagnosis of paranoid schizophrenia was the fact that I was escaping from a life that I was born into, do you see what I'm saying? My first reactions were very kind of limited and held back because of the space of which I was born into. And I took on a role growing up, my personality was retarded because of the social aspect of my life at the time. And I was wanting to escape from that and I was forced to things because – if makes any sense: if I didn't actually break out from my confines, my mental confine, and the social aspects of my life at the time, I would have committed suicide.

The voices of two sisters were based on two sisters that participant knew and had conflicting feelings towards

Participant was 7 when younger sister was born and thought she looked like no other girl he'd ever seen.

(D:64:3) The younger one I always felt I had an attraction for, even when I was a child. (D:65:1) I was kind of like 7 and she was just born, a couple of weeks old. And I looked at her and thought, "She looks like no other girl that I've ever seen, even as a baby, at my age at the time." I didn't think nothing, went away and watched her grow up.

When younger sister became older, he used to give her money for sweets

(D:66:17) the younger child used to ask me for money every now and again when I was the age of about 16 and 17. (D:67:1) I didn't have nothing against her, up to this day I don't have nothing against her...

Older sister had fallen out with participant's brother, and participant developed an attraction to her

(D:65:1) The other was round about my age. She was about 3 years younger. Her and my brother had some kind of falling out. My brother did something to her, I'm not sure what it was. (D:64:4) it come later, when I felt an attraction for her. But then because of the state of mind I was in I wasn't ready for any kind of relationships or anything like that...

Older sister falsely implicated participant in a local dispute when he was 7 or 8, which resulted in participant being whipped by his father

(D:66:1) I swore at one of the women in the area, I called her a C. U. N. T. When I was the age of about 7 or 8. And she went to my father and said that I'd molested one of her daughters. (D:66:13) he gave me, was it 10, or 20, lashings of his belt, and I pleaded with the same girl – the older one – “Tell him, was it me, was it me!” She went like that (*shrugs*). So I got 10, 20 lashings of the belt for something I didn't do. (D:66:16) They were the voices, it was her and the younger child.

Participant took older sister out at brother's encouragement, but felt sexually humiliated by her

(D:67:4) My brother like brought us together – my eldest brother. And she said that she's feeling alone, she wants someone to take her out. (D:67:6) I took her out once. But me and her could never make a connection, so she invited me around one time. She ended up cutting the back of my neck with a pair of scissors. And I took that. Didn't hit her. Didn't do anything. (D:68:1) I think it's because I was sitting there and was losing control of myself physically and mentally... (D:68:4) she showed me what I looked like in the mirror and I said, “Oh that's not bad, do this, do that” – she'd made my head look like shit, but I couldn't tell her. I passed wind and she cut my neck with the pair of fabric scissors. She opened the window, she said “ok then, now you've got to pay me.” So I give her the chocolate that she asked for and the cigarettes and I went about my business.

D13) Other recovery factors

Felt that the only way to overcome problems was to explore self

Feels that his illness was a legacy of his family circumstances, and the only way to overcome that was to experience it

(D:161:2) I think that what I experienced, I had to experience. I don't see it as- I don't know, I mean, I still feel that I was *ill*, how everybody else would have perceived me. I was ill. But that was what... was handed down to me from my parentage. I had to experience that to overcome it and to get on with my life. See what I'm saying? I had to experience that.

Didn't have the courage to commit suicide, so experiencing what was going on and finding out why it was happening was the only option

(D:123:1) At the time I didn't really realise it was that, it was just me surviving. I was feeling extremely suicidal. But I knew that I just didn't have the bottle to do it, so all I could just do was live. (D:118:6) I didn't know where the problem arose, and why I was experiencing them problems. And I wanted to experience, I wanted to find out why.

Would have spent life in care like mother, or locked in a psychiatric ward if he had not gone on journey of self-exploration

(D:117:1) I think that I did not realise that I was getting nowhere, and went on a passage of self-exploration, I would have ended up in her situation, being cared for by a carer for the rest of my life. (D:118:1) I think I would have been the same, maybe locked up in a psychiatric unit for the rest of my life.

Supportive social worker put trust in participant and instilled a sense of wanting to do good

(D:169:1) (My social worker) had a big, a big effect on my life, not effect, influence on my life, 'cos he put a lot of trust in me whereas most people wouldn't. And that impressed on me to do the best that I could and do, just do good things around me.

(D:169:6) I was being as positive as I could, and I think that's what helped me get past the fact that them members were no good for me...

Deciding to train as a counsellor

Social worker suggested training as a counsellor

(D:169:8) he was the one that recommended that I take up counselling, 'cos I said that I wanted to be, I can't remember, I was going round, I wanted to do some career and he said, "I reckon you should do counselling."

In training as a counsellor, has gained new insights into his own experiences of being in psychotherapy and some of the underlying issues

(D:170:1) I'm actually finding myself even more. It's helping me as a person, 'cos it's helping me understand the kind of therapy that I've had. And understand the reasons why, behind it.

Training as a counsellor has helped with self-esteem

(D:182:1) I just wanna help as many people as I can. People that have got some kind of mental health distress, or something like that. Maybe feeling a bit depressed and I wanna find ways of getting help to deal with that. That way I helped myself. Because when I started embarking on helping others in the community, I got more self-esteem for me. So it's for a selfish motive – it's to help myself.

D14) Once you're in the mental health system, it's difficult to get out

Participant feels he wouldn't be eligible for Disability Living Allowance if he came off medication, so there is a financial incentive to stay on it

(D:3:9) I get paid a certain amount of money to take it, with DLA. If I wasn't taking the medication, I wouldn't get DLA. Without DLA could I afford to live with my commitments with my family? I don't know.

It's hard to get out of the mental health system once you're in it

(D:4:2) Some people rely on the money, some people rely on the medication, some people rely on the therapy. Or some people rely on other stuff, I don't know... But it is very hard to get out of the mental health system once you get in it.

Rebelled against mental health system when younger, but only ended up deeper inside it

(D:4:6) before I was, didn't want nothing to do with it, I was dead set against it and I kind of like rebelled against it, and it was to my detriment. (D:5:1) Because eventually I ended up even deeper inside of it. See what I'm saying? Because I was clearly unwell.

Rebelled against mental health system because of negative stigma of schizophrenia, which carries a fear of violence

(D:5:2) I think the reason I rebelled so much is because of the stigma involved (*with the schizophrenia label*).

Participant E – Individual Depiction

(E) is in her early thirties. She had a brief experience of working with a clinical psychologist recently, but felt paralysed by the feeling she had to work in a way that fulfilled her therapist's expectations, and so ended the therapy. (E) had struggled at primary school because of a hearing problem. This had led to a feeling of being isolated and unhappy, and craving others' attention. When a man began to groom her sexually, she was glad of his advances. By the time (E) was twelve, however, she was having a sexual relationship with this man, who dominated her jealously and threatened to tell her parents if she ended the relationship. By the time it had ended, (E) was self-harming and was treated for depression. She had a brief experience of counselling at this point, but it did not seem to address the underlying problem.

At university, (E) began to hear the voice of her abuser, threatening to tell her new friends about what had happened. New voices joined the first voice, and (E) became paranoid that others could hear what they said. Her behaviour began to be dictated by the voices, such as the routes she walked and the food she ate. Unable to speak about the voices, in desperation, she admitted herself to A&E asking for a lobotomy. After a period of living in India and becoming involved in a religious order, she had another breakdown, which led to hospital treatment and being sectioned.

(E)'s experiences of being a patient led her to train as a psychiatric nurse, so that she could enter into the mental health system as a force for good. She feels that these combined experiences on both sides of the fence have given her an insight into the dynamics of the relationships between mental health professionals and patients. (E) currently has three concurrent diagnoses in the different NHS trusts that she has been treated in recently. One is Schizophrenia, in the second it is Schizoaffective Disorder, and in the third, Personality disorder. She has also recently received a diagnosis of Bipolar Disorder.

In her most recent breakdown, (E) thought she had been contacted by a psychic who was trying to enlist her in an intergalactic war between good and evil. She also believed her sister had been replaced by a robot, who needed to be destroyed. After being hospitalised for the fourth time (E) was offered psychotherapy with a clinical psychologist. She found him a sound person, and liked being able to communicate with him as a fellow mental health professional, but felt he used stock psychological responses, and that he became frustrated when (E) could not engage in the work in the way he expected. (E) began to feel paralysed by the situation and ended the therapy. However, she feels that this was partially because she was not ready to engage with her deeper issues, and still fears that doing so might lead to a meltdown.

(E) is an active member of HVN, and has found discussing her experiences with peers helpful. This has helped her to explore the links between some of her childhood experiences and her symptoms. For example, how the voice of the psychic who contacted during her most recent breakdown, seemed to mirror the old man who at first made her feel special, and then became abusive. At the same time, (E) finds that while the trauma model of psychosis used by HVN was useful to some people, she felt her own experiences might be better explained as an ability to communicate psychically. However, she also feels this interpretation may be motivated by a desire to find a more positive explanation for her voices than an illness interpretation.

E1) Participant experienced trauma in childhood

Experienced emotional problems from an early age

(E:17:1) it was strange. I was always quite unhappy. I mean my mum will say this, I was basically born unhappy (laughs). I came out screaming. I screamed for the first, God knows, how ever many years of my life...

Primary school period was unhappy

Primary school age was an unhappy, sad and overwhelming period

(E:17:5) To be honest, in a way I think I remember my primary school age, the youngest of my life, as being even more unhappy than the teenage years, which were pretty fucking unhappy. Like I struggled with everything. Like I don't have really big memories of it. But the memories that I do have are all sad and it all just like, overwhelmed, I just don't understand what's going on. I don't understand how to fit into this.

Had hearing problems at primary school that may have made fitting in more difficult

(E:17:16) Even now I don't know what that was about. I know that I had a lot of hearing problems when I was very little. So I think that's why there were problems when I was that age. And then I had my adenoids out and I could hear. (E:17:20) that's what my mum always puts it down to, something to do with my hearing.

Didn't know how to get people to notice her

(E:17:11) I just felt really just like I didn't know what to do to get adults to notice me and like me, to get other children to notice me and like me. To feel like- my mum thought I was autistic or had Aspersers or something. She was really worried about me.

Bullied at primary school

(E17:3) I had loads of emotional problems all the way through junior school. And consequently was quite left out and bullied and targeted, and I struggled a lot. (E:8:1) I had a pretty shitty time at junior school. Like I didn't have any friends...

Self-harmed at primary school

(E:8:11) these metal bits on these ring binders... I remember peeling those off one of my mum's folders when I was little. And I knew – this was when I was like ten, 9 or 10, junior school definitely – and I was in the classroom I was cutting with those. And I knew that I was doing something really naughty and I didn't want the teacher to see of my friends to see, but I didn't really know what I was doing, but I liked doing it and it helped.

Was vulnerable to being groomed for sex by older man who could see she was unhappy

(E:8:16) I was very sad when this guy came into my life because that's how he got his way in, because I was really not feeling good and he was like flattering me and things like that and comforting me. (E:9:10) there was this one day where I was sitting on this wall. I must have been really little because sitting on the wall my feet were like dangling off there, and like, it springtime, and I was crying. (E:9:14) and he came up to me with this whole bunch of – it's funny, it's still like a fond memory, which is

weird – with this little bunch of bluebells, and was like, “You’re really beautiful, you know, you don’t have to be sad.”

Sexual attention of older man was welcomed at first

Had never been told was beautiful so sexual attention of older man felt positive

(E:9:1) I don’t think anyone had really told me I was beautiful- maybe my parents or something, but I wasn’t really ever beautiful. I wasn’t a beautiful child. I was kind of quite tomboyish and nerdy... (E:10:12) it felt good to start with, and I guess he earned my trust.

Relationship with older man started as innocent and became sexual

(E:12:7) he was so positive in a really innocent way for about a year. And then really positive in a really un-innocent way for probably another year or so. Like everything was ok because I was just learning and I was new and it was lovely because I was young.

Relationship with older man initially boosted self-esteem because participant secretly knew she was more sexually advanced than her peers who had teased her for not being pretty

(E:11:1) people would maybe take the piss out of me at school a bit because I wasn’t one of the pretty people, or the cool people, the people who were like snogging boys at parties, or whatever. But I secretly knew that I was, and I was actually doing more than they were doing. And they didn’t know that and I was like, you know, somehow this is clever and cool and grown up because I’m learning to do all these grown up things.

At the time, didn’t think of relationship with older man as sexual abuse

(E:12:1) I didn’t think there was anything happening like abuse, just kind of like, “Oh, what’s wrong with me? Why am I involved with this guy who’s like my parents’ age and my friends have these like young boyfriends and things. And why am I doing this stuff where I’m hearing people calling girls slags for doing, and I’m doing it because I thought it was ok?”

Relationship with older man became coercive

Older man attempted to control participant’s relationships

(E:12:17) he was very much like, “You do not do this with anybody else. You do not have boyfriends. You do not do what your friends do. You do not practice in your spare time (*laughs*). You do not, you know, like, this is all there is.”

When older man became critical of participant, relationship felt like a mirror of earlier feelings of being useless

(E:12:10) then it was this next phase with like, “Well you’re turning into a woman now, you’ve fucked this up, you’re not doing this right, you’re not satisfying me in this way, you know. If I had a proper woman then she would know how to do this.” (E:12:14) at the time I was like, “Oh my God, I can’t even do this right and this is the only reason he likes me and if he doesn’t like me then nobody likes me and I can’t have anything normal because I’ve got this.”

Older man threatened to tell parents about the abuse if participant tried to end the relationship

(E:23:18) he was like, “Well if you stop doing it I’m going to tell your parents everything you’ve done. I know where they live. They in S***** road. And I’ll go and knock on the door and I’ll tell them.” (E:23:22) and that made me too scared to stop or to... You know, because I thought that was what he would do.

Sexual abuse ended when participant was 16 and moved to another school

(E:18:7) he was a problem for me til I was 16. And I then moved to a different school for sixth form. And stopped going past where he lived, and just cut him out. It was that simple.

Didn’t see it as abuse at the time, but knew it was wrong and managed to forget about it for 10 years

(E:14:3) (It wasn’t until) over 10 years later that I acknowledged that it had happened, let alone actually talking about it. (E:14:25) my version in my head of what childhood sexual abuse was completely different to what happened to me, you know. What I did was this very, very wrong thing that I actually managed to really effectively forget about, you know, consciously forget about for a very long time.

E2) First contact with mental health services in mid-teens

Being sexually abused by older man triggered depression

Attempted suicide when felt unable to leave coercive sexual relationship with older man and was diagnosed with depression

(E:8:7) around the time I first hit mental health services was when things had started to go quite wrong with him, which left me feeling really quite isolated. (E:10:1) it was all quite fucked up. (E:11:8) gradually it got to the point where I was realising, “I’m stuck in this thing. It probably is a bit wrong. It is a bit horrible and disgusting. It isn’t what I want. It is probably a bit horrible and weird.” And that was probably the point when the overdose happened... (E:13:6) after that I got diagnosed with depression (*laughs*), and given Prozac.

When first came into contact with mental health services there was a suspicion of abuse, but didn’t speak about abuse because didn’t see it as abuse at the time

(E:14:5) I was asked and asked, and asked and asked. Like, you know, “Have you ever been abused? Are you being abused?” My parents were put into different rooms so that I could be asked if my dad was abusing me, my mum was abusing me, my parents abusing me. And that seemed to happen a lot, they wouldn’t take no for answer. So I think they *knew* but they couldn’t get me to say. But that was because I genuinely didn’t know. I don’t think I was hiding anything or protecting anyone.

E3) Secondary phase of trauma in adolescence

Felt unhappy and isolated at sixth form college

(E:178:10) I was very unhappy for the whole of sixth form. Very unhappy and really isolated, hardly made really any friends and started just doing loads of exercise.

Didn't really go to college that much because they gave us the syllabuses for our A levels and all the teachers were shit.

Developed eating disorders

Eating disorder began aged 17

(E:18:4) I'd always been, like, really, really naturally skinny. So I'd always been able to eat as much as I wanted to and still be really skinny. I used to do a lot of exercise, but I always think I naturally was. Then I got to 17 and started to put on weight.

(E:19:1) which I think is perfectly normal when you get to 17. But it had never happened to me before and I was so greedy. So I immediately went to bulimia and then I was still really bulimic for the first year of university. And then I worked out that the only way I could really manage that was to starve myself, and then I was really thin.

Was anorexic not because she had body dysmorphia, but because she wanted to make others jealous that she was so thin

(E:19:7) I never had that body dysmorphic thing of thinking I was fat. I knew I was really fucking thin, I knew I was really unhealthily thin and that was how I wanted it. And anybody who challenged me about it was jealous (*laughs*). Even though I really looked *bad* (*laughs*). Like that was my interpretation, "Everyone wants to be skinny, I'm really skinny, you can fuck off!"

Confused about whether or not she was raped by a male friend when 18

(E:25:22) when I was 18 I was raped by quite a close friend of mine. A guy who I cared about a lot. (E:25:27) something had happened with another girl as well and she told everyone and everyone was turning their backs on him, saying "T**'s this, T**'s that, da, da, da." And I think he's just a bit muddled up with things. So I'd gone to visit him at his parents and then something had happened again. But I don't know if it did or it didn't or if it was a dream, or I don't know.

E4) Experienced a breakdown in 3rd year of university, and first started hearing voices

First voice heard was that of abuser

Abuser's voice appeared outside bedroom door

(E:23:1) I was in my bedroom. I had this really huge room. I was at university at E*****, we used to have this massive flat with no central heating. (E:23:11) I just woke up and I could hear this voice outside my bedroom door and it was the voice of this guy, you know from when I was younger.

Abuser's voice threatened to tell her new friends about abuse in the past

(E:23:18) he was like, "Well if you stop doing it I'm going to tell your parents everything you've done. I know where they live. They in S***** road. And I'll go and knock on the door and I'll tell them. (E:23:22) and that made me too scared to stop or to... You know, because I thought that was what he would do. (E:24:1) This is pretty much what he did when he came to my room that night in E*****.

Hid all night in wardrobe to try and escape voice

(E:25:5) I went and hid in my wardrobe, to be like further away, to not hear him. But then he got in the room and then I just stayed in my wardrobe all night until it got light. (E:25:8) And then I hear my flatmate get up from the room next to me. And I could still hear this voice, but it started to seem a little bit less real. So I got out of my wardrobe and went and talked to my flatmate. And then the voice had gone.

Other voices began to join the voice of abuser

(E:25:20) then it started happening every night. (E:25:21) Like voices that I hadn't heard before, voices that I had heard before. (E:25:33) And other really unfamiliar voices talking about things. (E:26:1) I can't remember which ones exactly were there, which ones all came since. But there was a lot of them

Voices are experienced in differing proximity

Voices are always external, but feel like they vary in proximity, from very close to very far away

(E:30:1) I always hear voices from outside. They're like, if I do that (*covers ears*), they get quieter. They're very external. Very external. Always have been. All of them. Thank God I've never had the internal ones, 'cos I don't even know what you do about those... (E:30:4) I hear them from far away and I hear them from close and I hear them from far away getting closer, and hear them from *really* far away so that I don't know how I even manage to hear them. I hear them from really close so that I can really feel almost, not breath, but the air on your ears when...

Abuser's voice is experienced as the closest in proximity

(E:31:1) I get that mostly with his voice actually. The other ones are usually a bit further away. Feels all warm and creepy...

Unable to discuss voices, and felt isolated and scared

After voices began, felt lonely and difficult to be with

(E:36:6) it was really lonely, it was the most lonely I'd been through the whole of university, 'cos I'd actually been getting on ok. You know I had friends and stuff, but I was just like a bitch, I was such a bitch that year, I pushed everyone away from me. I was just like constantly snapping at people... (E:36:12) I don't know if that was being paranoid, or being deliberately paranoid, or what.

The conviction that other people could hear voices made it more stressful

(E:29:1) I was *so* stressed. And I always had this thing, like, and I still have this now, but it was more acute then, where I felt that other people could hear the voice. And *he* would be telling these things, you know, of my past, that I was so ashamed of, really loudly when I was sitting next to somebody who was a friend of mine. Because obviously the way I believed about then, I thought what he was saying would fuck that up. So I would just be doing things like being like, "Sorry, I can't talk to you now!" and just running off, because I didn't want them to overhear...

Coping mechanism was to ensure was never alone, because unable to talk about voices to other people

Tried to never be alone, which felt shameful

(E:36:18) So I will be here hanging out with people who want to shake me off. Which is so, so embarrassing and so shameful, but I was like trying to survive. Yeah, so that was probably a bad phase.... Pretty bad.

Because unable to talk about the voices, initial method of coping voices was to ensure that she was never alone

(E:26:3) pretty much what I did was go, "I can't be on my own. Like I'm fine as fine as long as I'm talking to people." But then I just ended up doing that kind of horrible thing of hanging out people, regardless of whether they wanted me there. (E:26:9) I did lots of tactical passing out (laughs), because I didn't want to go back to my room. But actually there where I was and I would be having- just really chaotic and walking, walking miles, waking up in places where I didn't know where I was.

Voices began to dictate behaviour

Voices claimed to have moved things around, or would dictate lengthy walking routes

(E:35:6) they were also doing little things like moving things around to make me know that they were there, and then telling me, something dangerous was around-kind of like giving me warnings I suppose. (E:35:9) so I'd be going to like the swimming pool and I'd have to of gone around so many other corners on the way I was supposed to go. And like an hour later I would be miles away from the swimming pool and miles away from my house, and just going like, "Aaaaarggg."

Voices expressed paranoia about poisoned food and dictated what she ate

(E:35:19) they also started off with this poisonous food nonsense, which I hear loads of people get, like "That's poisonous, that's poisonous." (E:36:1) So I was eating really particular foods out of particular packets that were particular colours and stuff.

Taking recreational drugs and not looking after self at time of breakdown

(E:25:17) I was also like taking a lot of drugs and drinking a lot as well, like I was really not looking after myself.

Managed to graduate from university despite voices

(E:35:14) I got through my final year and I graduated, but like, the lifestyle was really ridiculous. Like getting up, waking bolt upright with the voices waking me up at 5 'o' clock in the morning, going swimming, or running.

E5) First contact with mental health services after hearing voices

Attempted to receive treatment at a general hospital, by asking for a lobotomy to remove part of the brain where she thought the voices were coming from

Presented self at A&E asking to have a lobotomy to remove voices

(E:26:13) went into A&E, asked them to cut a section of my brain out where I'd decided that the voices were coming from. (E:33:1) I think they sedated me and then, I woke up in the morning on a general ward. I think in the same ward where you would go if you had an overdose or something. I think I'd had a couple of overdoses by then, so I think... It was familiar.

Waking from sedation, couldn't hear voices anymore and realised that she needed to leave hospital because it was a frightening environment

(E:33:11) I actually couldn't hear any voices when I woke up. So I was kind of able to think enough, "Shit, this is gonna fuck me right up. This is not good, being here in this situation." And it felt horrible as well. The whole environment of that ward was really frightening and unpleasant.

Bluffed way out of hospital

(E:33:20) I just blagged my way out of it basically. And they were like, "You were saying some pretty strange things. And I was like going, "I don't know what that would have been about. That doesn't sound like me. You know."

Voices got worse when not treated

Voices got more threatening when not treated and influenced behaviour more

(E:34:8) But I wasn't fine, I was far from fine. So I went home and the same thing carried on with the voices; it got worse. (E:35:1) they started to be more threatening. (E:35:2) they were really threatening, and they were kind of beginning influence my behaviour more.

E6) Medication has little effect on voices, but recreational drugs have some effect, both positive and negative

Medication does not block out voices

(E:46:5) even with all the medication I've ever been prescribed – I hear voices every single day and it's like a shock if I don't.

Not drinking or taking drugs altered how the voices were experienced

(E:39:1) (In India) I wasn't drinking and I wasn't taking drugs, so what I was experiencing was the same, but different.

Relationship between recreational drugs and voices

For 2 to 3 days after taking MDMA does not hear voices, but then they come back with a vengeance

(E:46:2) if I take MDMA, I tend to feel a bit high for 2 or 3 days before I come down. In those 2 or 3 days, I will quite often not hear voices at all- or not any, which is practically unheard of for me. (E:46:10) Then they come back with an absolute vengeance and punish me for the bit that I've missed. And it is worse.

Realised that recreational drugs had serious depressive effect

(E:44:1) (*After return from India*) I'd got more in touch with the fact that the drugs were doing the fucking about with my mood a lot and causing extra problems...

E7) Experiences of psychiatric diagnosis have been contradictory, confusing and often unhelpful

After a series of other psychiatric diagnoses when younger, including depression, anorexia and bulimia, was immediately given schizophrenia diagnosis after hearing a voice in 3rd year of university

(E:5:6) And then voices started, and it was *immediately* – bizarrely – it was immediately schizophrenia...

Feels that schizophrenia diagnosis is not representative of her experiences and is given when people don't know her

Annoyed when given the schizophrenia diagnosis again recently, because feels it doesn't apply to her

(E:4:13) I was like, "I don't have schizophrenia" - I mean, I know that I don't have it anyway and I usually just ignore the diagnosis – but for whatever reason the hospital makes me much more medical model anyway – I said, "That's not my diagnosis" and I made him like go and prove to me that it was...

Feels that schizophrenia diagnosis was based on a limited impression of her

(E:4:18) I guess it's because, maybe they didn't know me for very long, or it was the way I was presenting, or whatever they decided it was.

Has a schizoaffective disorder diagnosis in the trust that she works in, perhaps because they know her better

(E:4:20) I know that when I was in W*** L****, where they've got me as schizoaffective, apparently I was really high. Apparently, I was really paranoid with bad voices and stuff, but apparently I was really elated as well. (E:4:24) I guess the trust that I work in, that I, the team that work with me that see me the most, see more of my personality.

Prior to her own diagnosis, participant had negative perceptions of the schizophrenia diagnosis

Participant had a fear of schizophrenia diagnosis because of family members who had received the diagnosis killed themselves

(E:5:8) I've got quite a strong family history of schizophrenia and bipolar... (E:6:1) the people who had schizophrenia in my family were two relatives who both committed suicide...

Other examples of people with schizophrenia diagnosis who participant had met were negative

(E:6:16) There was one other guy at university who I knew through a friend, who I knew had a schizophrenia diagnosis and he was just horrible. Like he was just really, really aggressive. Really threatening, just a really unpleasant man.

Not fussed about schizophrenia diagnosis, but is careful how she presents it to others

(E:2:19) I'm not particularly fussed about my diagnosis from the point of view I don't particularly believe that it makes- well I believe that it makes a massive difference to me, who I am. I understand diagnosis as a tool. I will talk to people who I don't know well, or who I need to present a certain version of events, in terms of packaging up

my experiences in my diagnosis and transmitting that. So like my employers, and the DWP (*laughs*). But probably as a general rule, I'm not that affected by it.

Personality disorder diagnosis is worse than the schizophrenia diagnosis

Personality Disorder diagnosis has a strong stigma attached to it

(E:63:1) certainly, all references to personality disorder are really derogatory. Like that's something I always have been acutely aware of.

Nobody deserves a Personality Disorder diagnosis

(E:3:1) because I work in services and I know what attitude people who work in services have toward people who have personality disorders (*laughs*). (E:3:4) I think it's a stupid diagnosis that nobody deserves, *ever*...

Angry that not consulted when given personality disorder diagnosis

(E:2:24) when I found out that when I had this personality disorder thing and nobody had literally *ever* mentioned to me, I was like "pffff – what's that." (E:3:1) I was really angry about it.

Challenging mental health professionals leads to being given a personality disorder diagnosis

If you understand the system you have to challenge it to survive and this often attracts a personality disorder diagnosis

(E:4:31) You know, you put your personality into things, and you know your rights and you argue your rights and you take care of yourself and you give people a bit of trouble. And then they go, "Hmmm, that's a personality disorder." (E:4:26) I know that's how you pick up a PD diagnosis, just by asking too many questions, not doing everything they say, working out how the system works.

Being angry in hospital led to being diagnosed with Personality Disorder

(E:3:15) a couple of examples of things that he *consultant psychiatrist*) thought might have led to it, were examples of me behaving badly in hospital. And you know, I was like, "Well, sorry if I broke some stuff when I thought I was in a concentration camp and I wanted get out."

Bipolar disorder diagnosis is seen as more acceptable than schizophrenia

Has also received bipolar disorder diagnosis in face to face meetings with psychiatrists because it is often perceived as less threatening than schizophrenia, which participant feels was given behind her back diagnosis

(E:3:6) (psychiatrists) whilst firstly diagnosing me with schizophrenia and schizoaffective disorder, were talking to me about bipolar disorder, like they were using that term to talk to me because it's a less threatening term, whilst behind my back diagnosing me with schizo this or schizo that, while not doing that to my face.

Bipolar diagnosis seen as less crazy than schizophrenia diagnosis

(E:7:1) bipolar was seen as – and it still is – as "Yeahhhh" you have your ups and your downs, but you're not like, completely crazy, someone who's like going to drive their car off a cliff one day for no particular reason, or somebody who only talks to you through their dogs, or whatever.

Campaigned to get schizophrenia diagnosis changed to bipolar because more acceptable

(E:5:10) they went to bipolar but I think that was a little bit because I campaigned for it (*laughs*). Because I was like, “Arhhhh”. I don’t know whatever was going on I my head, I just really didn’t want this schizophrenia thing, and bipolar was a little bit more trendy.

Participant has 3 concurrent diagnoses given by different psychiatrists, which is confusing and contradicts the logic of the diagnostic system

Participant currently has a different diagnoses in each of the 3 NHS trusts that she has been treated by in last year 1) schizoaffective disorder 2) schizophrenia 3) emotionally unstable personality disorder

(E:2:8) I’ve been treated in three different trusts in the past year. (E:2:10) in W*** L***, my diagnosis is very clearly schizoaffective disorder without any other diagnoses. In S**** L**** and M****, it’s very clearly schizophrenia, without any other diagnoses. And what I didn’t know – because nobody’s ever spoken to me about it or suggested, in the trust where I was treated earlier this year, my working diagnosis was emotionally unstable personality disorder, which nobody had *ever* mentioned to me at all.

Although not bothered by having a diagnosis, which one is chosen dictates treatment offered, and that does matter

(E:2:30) I’ve got this collection of diagnoses and whoever is going to treat me is going to just choose one, then that does matter, really to me.

Diagnostic logic is currently being broken by being given anti psychotic medication for Personality Disorder, which is supposed to be treated with psychotherapy

(E:3:19) why lie to me and why medicate me? Because you’re not actually supposed to take medication if you have a personality disorder, you’re supposed to get loads of therapy. That’s what they say in all the guidelines, so why am I being treated for a psychotic disorder if I now have a personality disorder?

Grateful that current psychiatrist is more flexible with diagnosis

(E:4:4) I’m kind of grateful, the service I’m under at the moment, the consultant I’m under at the moment, who is very medical, but quite well meaning and is a little bit more forward thinking than some consultants, is prepared to kind of just stick one diagnosis on me, but kind of work around and about those.

E8) After first breakdown, went to India to reinvent self

Got involved in a religious order and became preoccupied with themes of good and evil, guilt and repentance

Went to India after breakdown and was un-medicated for 3 years; felt focussed and free

(E:37:1) I then went abroad for a couple of years once I’d finished uni. (E:38:1) (I went to) India. I spent a year in Bangalor and a year in Calcutta. So I was un-medicated for those two years. (E:39:2) when I first got out there, everything was amazing, really good. It was why I stayed so long. Everything was like intensely

colourful and waking up and like being free and away from all the crap, and you know, having focus.

Becoming immersed in Catholicism gave a religious framework to feelings of self-hatred and desire for forgiveness

(E:39:12) I went to Calcutta, to do the Mother Theresa volunteering, you know with the missionaries and stuff. Of all things, to go to India and discover Catholicism (*laughs*). (E:39:14) Catholicism sold itself to me so well. I mean, like, it's like a religion where you get to be evil and hate yourself, and beg forgiveness every day for the evil sins you've committed, you know. And everything you've done and everything you've failed to do. And it just drank me up...

Began to interpret the voices as religious and that changed their character

(E:39:8) I was still hearing the voices, but I was starting to like interpret them as being religious in nature. So I started thinking, these were the voice of the devil, the voice of God. And the voices, I suppose, changed their character a little bit. They started talking about sin and forgiveness and repenting.

Wanted to become a nun so that would never have to have sex again

(E:40:8) I was doing all this religious stuff, and then... I wanted to be- but it wasn't enough, I was like, "Well, I want to be a nun. You know, this is going to be great, I'm never going to have to have sex again!" (*laughs*).

Started to believe she was Mother Theresa and things began to go wrong

(E:40:1) after this period of time in Bangalore, which was quite nice I worked for an Indian NGO, made lots of really good Indian friends and western friends... (E:40:4) I was like, "I must go to where Mother Theresa is". And I went through this weird phase where I thought I was Mother Theresa, and basically when I went to Calcutta it all went wrong.

Had a second breakdown when rejected by religious order

Religious order could see participant was mentally unwell and cut her off

(E:40:11) they could obviously tell that I wasn't really mentally that well. And they actually were really, really, really profoundly intolerant of that. They pretty much banned me. You know, I don't know what else they were supposed to do.

Experience of life flipped from being Godly to hellish

(E40:16) everything kind of flipped over and went from being all Godly and wonderful to being all demony and hellish. And everything stopped seeming bright and colourful and cheerful...

Voices changed from driving participant to atone for sins, to accusing her of being fundamentally sinful and therefore without hope of atonement

(E:41:1) When I look back on it, the character of the voices - it felt like it had changed. But I think they were still saying the same thing, but I felt like I deserved it, so it made sense. I was like, "This is my pathway to *salvation* is by like listening to what the voices say, believing it, acting on it, changing myself, recovering, becoming a better person, putting my sins behind me. You know, moving on becoming a better person." And then once that door was locked to me, in a way, the same voices were kind of basically *you*. *You're* basically fucked, *you're* sinful, there's no way out of

this, this is your lot, you know. You fucked it up. It's too late to change it round, the door's been closed. You know, deal with it.

After second breakdown in India, moved back to UK and moved in with boyfriend and began taking hallucinogenic drugs

(E:42:1) I moved back to the UK and I moved to S*****, where I moved in with my boyfriend, who was a kind of long-term on-off boyfriend from when I was like 17. (E:42:10) and... it was back how it was in Edinburgh really. I was just really, really drinking a lot, taking a lot of drugs... (E:43:1) Mostly MDMA, coke and mushrooms bizarrely. (E:43:5)

E9) Mixed experiences of being a service user spurred participant to want to work in mental health and be a force for good

Mixed experiences of mental health system made participant want to be one of the good ones

(E:55:16) I'd been on the receiving end of good and bad mental health services from the age of 14, so this is like over ten years later, with the exception of when I was in India, pretty much going, "Yeah, there are good people and there are shit people, like I could work in mental health and be one of the *good* ones."

In attending hearing voices network groups, found that she was able to help others, and encouraged her to try and change the mental health system from the inside

Attending groups built on intent to work in mental health

(E:55:1) I started going to a Hearing Voices group in S***** and, I think already somewhere along the line someone had told me about mental nursing. I knew I wanted to work in mental health *really*, from actually quite a young age. I think from actually kind of the first depressive episode...

Fell into a facilitator role at groups, which encouraged participant to train as a psychiatric nurse

(E:55:9) I started to find that I was quite quickly falling into that kind of counsellor-y role in the Hearing Voices group. Cos I was actually working. Compared with some of the other people in the group, I guess kind of, I seemed to be doing pretty well. I had a boyfriend, I had a job, I was functioning. (E:55:14) people were saying, "it would be so good if someone like you was a nurse".

Hearing Voices Network encouraged participant to try and change the mental health system from the inside

(E:55:19) with a bit of this changing the system from the inside idea that I was picking up from the Hearing Voices (group). I was like, "I could be a bit radical, I could work in the system and be one of the good people and like change the world" – pretty grandiose.

E10) Experienced a third breakdown during psychiatric nursing training

Found mechanised, impersonal, and sometimes disrespectful approach to service users disturbing because it raised question of whether mental health professionals thought about her in the same way

Found mechanised approach to treatment taught on psychiatric nursing training disturbing

(E:58:27) first of all was the teaching in university where you just get taught, “This is schizophrenia, this is bipolar disorder, this is this, this is the treatment for this, this is the treatment for this, off you go.” That’s pretty horrible. I found that really quite disturbing. (E:59:7) I was like, “I can’t believe this is how you talk about people who are in your care.’

On placement in a psychiatric ward, found disrespectful way that professionals talked about service users disturbing, and wondered whether she had been talked about in the same way

(E:60:4) they were just like, making jokes about things people said, about people’s beliefs, about... ‘Cos you know, obviously quite a lot of people have kind of, beliefs or whatever, that are based in sexual things and stuff, and like making jokes out of those, um... Laughing at people who are overweight – which is obviously most people on anti-psychotics, laughing at people who- like so, so unpleasant, and I just couldn’t deal with it at all. (E:58:21) I wonder how many people have gone like, “Phew, sounds like an Inny” (*inpatient*) about me.

Told that disrespectful approach to service users is how professionals deal with stressful job, but then called into question whether people who had inspired her had also talked about her in the same way

(E:60:9) I spoke to my tutor about it, who was a good guy, but he was like, “This is part of how people deal with doing a really stressful job.” (E:60:12) But that just made me more worried, because I thought of all the people- some of the inspirations, the people that I’ve met who made me want to be a nurse, was that how they talked about *me*?!

Build up of issues connected with experiences of mechanical and sometimes disrespectful approach to service users during psychiatric nursing training led to breakdown

(E:59:1) I think before I even went on my first placement, I’d overdosed for the first time in years, just having a really terrible time with emotions and voices. And it was fine, it was managed very well, you know, “Took this overdose, what the fuck have I done”, J*** sorted me out, took me home, took care of me. It was ok, I didn’t really know what had happened, but now I would make sense of it as a building up of those kinds of things.

E11) Where psychotherapy has been unhelpful

Felt prepared to talk about self conversationally in therapy with clinical psychologist, but was cautious of what benefit there could be

(E:50:11 – E:50:17) (*After prevaricating at the suggestion of seeing the care team’s psychologist* (E:50:15) I was like, (*sighs*) “I don’t really know what about. I don’t

really know what to *do*. I don't know, do you think I should see him?" And she was like, "I don't know, you know, do you?" And I was like, I kind of feel like, you know, "I don't mind sitting and talking about myself, you know, like *this*. This is nice. So I was like, "Well, you know, I can talk to him, but I don't know how helpful that would be."

Discussing issues with clinical psychologist in terms of psychological theory, which participant was conversant in, felt comfortable, but didn't feel like it was changing anything

(E:52:13) It didn't really feel like it was changing much, but it was kind of interesting. It was like, "Good theory, that's nice" um...

Stock psychological responses from clinical psychologist felt unhelpful

(E:50:22) he was really sound, but such a psychologist. Like everything had this like stock psychological response to it.

Felt there was a pressure from clinical psychologist to engage in the therapy and wasn't able to commit

Pressure from therapist to make a decision to opt into the therapy

(E:53:1) apparently I have a problem with making decisions. So he was trying to make me make the decision. And I didn't- I was paralysed, I do not know what the right decision is. I just don't know. I don't know if I should stop or if I should carry on. And he kept putting the ball back in my court, and giving me another session to decide. And *another* session to decide. So I was kind of in this like, he was not going to have it that he was going to decide. He was like, "No difference to me, we can keep going like this. I don't think you can do this work until you can opt into it. But I'm not going to go away until you opt out of it."

Therapist's pressure to get participant to commit to working with voices led her to end the therapy

(E:52:14) I stopped seeing him was when he was like, "We can do this work with your voices, but you kind of have to commit to it. And you have to have some kind of expectation that it will work, or it won't work." So I went away and I really thought about it for a couple of weeks and I went back and said, "Phhhhhh, I don't think it will work. I'll really miss coming and I partly want to pretend that it will work because I want to keep coming and it's nice to sit and talk about myself, like you know, but it's probably better if I don't." So that's where it ended really. So it kind of felt like it ended in nothingness in a way.

In hindsight, feels wasn't ready to engage in therapy work with clinical psychologist because of fear of touching on deep, unresolved, and painful issues

Felt that clinical psychologist wasn't prepared to work with her unless she was prepared to work on something

(E:53:12) the truth of the matter was that I was not prepared to do that piece of work. And the truth of the matter was that he wasn't prepared to keep working with me, if I wasn't prepared to work on something.

Felt that touching on deep issues in therapy would make her incapable of being able to work

(E:53:14) I quite liked the chatting. I didn't really want- and I made it quite clear to him in the beginning, "I'm not really signing up to any deep shit. I can't do it. I've got a full time job, can't be going into all of my issues. But if there's something kind of a little bit less deep that might be helpful. Some techniques, or whatever, then that's cool. But I'm not going there with the serious stuff; not while I'm working."

Fears that exploring deeper, more painful issues will lead to complete meltdown

(E:54:1) I go through this debate all the time with people, especially my boyfriend, who's obsessed with the fact that I can't possibly get better unless I do deal with my shit. But I'm like, "When?!" You know. If I've got like a couple of years to have an actual meltdown and a rebuild, ten maybe I would do that. But I'm not going to risk my social life, my love life, my job, my financial situation, my housing, to have an actual complete, you know, meltdown.

Feels that current fixed interpretation of voices keeps her safe and fears anything that might challenge that

(E:50:6) (Current care coordinator wants to) Change the way I understand them. Trying to have a more healthy relationship with them, or a less distressing interpretation of them. And I always used to say, "Look, it's a bit late, I've been hearing them for quite a long time; I'm quite fixed in my interpretation of them. And I think my interpretation of them keeps me safe."

Feels she is squashing issues down into a box because she can't face them, but fears that they will have to be faced one day

(E:53:7) I know it sounds like probably to a psychotherapist that sounds really unhealthy, because I'm like, "Squash it into the box, put it all..." I don't know. Either there will be a time when I choose to address it, or there'll be a time when it bites me in the ass and I have to. In the meantime, I'm just going to keep my shit together.

E12) Where psychotherapy has been helpful

Clinical psychologist had some helpful perspectives on issues

(E:50:23) he gave me some quite helpful perspectives on things that came up.
(E:51:4) I don't really remember what they were, but I remember that I would be talking about something and he would come up with like quite a useful insight. And I would be like, "Oh yeah, that's not rocket science is it. That's probably why I do that." (E:52:2) he would be like, "That's interesting, because there's this theory that yad, yada, yada. And there's this other theory that yada, yada, yada. And then I'd be like, "Oh! That kind of makes sense, because that kind of relates to yada, yada, yada."

It was nice to be able to communicate with clinical psychologist as a fellow mental health professional, and not go into things that participant already knew about

(E:52:5) the thing is, I've got a psychology degree, that's undergraduate degree, that's got nothing to do with clinical psychology, but I've got that kind of training, and I work in mental health, and I've got all my involvement that I've had from working with Hearing Voices, things like that. So he as very much communicating with me as

somebody who had that understanding. Which was really nice, because you know, he wouldn't be going into things that I already knew about.

E13) Non-clinical factors that have been therapeutic

Exercising washes away the voices

(E:35:17) Doing some form of exercise, which makes the voices wash away, or pushed them away, or drowns them out, or whatever.

Values relationship with care co-ordinator

(E:50:1) I've got a really good care coordinator, really nice. Really cool. Like probably the only good mental health professional I've ever had, and she's really smart...

Relationship with boyfriend has been supportive and helped keep participant safe

Boyfriend helped keep participant safe, even when she was hard work

(E:57:1) J*** managed – J*** managed me (*checks medical speak in regard to relationship*) – J*** and I managed *each other* quite well. I know I was quite difficult. I know he gave quite a lot to... He was really anti mental health services, and he did some ridiculously lovely things to keep me safe... (E57:11) I was *not* very well (compared) to the way I am now. I was really hard work.

Relationship helped participant to feel supported through episodes of paranoia

(E:58:1) I was frightened a lot. And I had a lot of very strange ideas about things, and... You know, I made us have newspapers over the windows. I mean, we used to live in darkness for months with newspapers on the windows and keeping this catalogue of all this information that I was collecting. I used to accuse him of things as well. Like, moving things, or setting things... Just really obsessed about things. And I thought he could hear the voices so much, and when he denied it I would get really angry because I felt he was patronising me.

E14) Working as an NHS community psychiatric nurse, as well as still being an active service user, has brought up complex issues around self-disclosure, and treatment ethics and politics

Finds that mental health professionals can be disrespectful when talking about service users

Community mental health teams are more respectful and less stressed than inpatient teams

(E:60:19) I went into a community job and it wasn't anywhere near as bad. People in the community were much less likely to be disrespectful, seemed to be taking everything much more seriously...

Participant's manager says outrageous things about service users, despite knowing participant's diagnosis

(E:62:1) I'm dealing with all these quite qualified, experienced, very caring-seeming nurses, and I'm back in that thing of nobody knows my diagnosis or my personal

experience, apart from my manager who had to be told because of the occupational health song and dance all over again... But even she, who *knows*, says the most outrageous things in front of me, where I'm like, "I can't fucking believe that everyone else in this day and age isn't even considering there might be somebody in the room who's experienced any of these things"...

Felt comfortable talking about own diagnosis with NHS colleague who also had a mental health diagnosis

(E:61:1) it was very much a written understanding that I had a diagnosis- and actually my colleague had been diagnosed with depression as well, and you know, it was a little bit like making fun out of ourselves in the context of, "Yep, we're all mad. Whatever."

Reluctant to discuss own diagnosis and experiences in working relationships with NHS clients

Is very cautious about disclosing diagnosis to clients

(E:68:6) In my role as CPN I'm kind of very... apprehensive, I suppose from just about a general, "I work for the NHS", you know, risks, best interests, whatever, point of view. Like I would feel that I would have to discuss that with somebody else and decide that was a good idea, rather than just bring it in.

Self-disclosure in work is limited to referring to a hypothetical person

(E:69:16) it's not like psychotherapy. We're not taught very much in nursing. Like how to use ourselves. And I do try to use myself to a degree. And what I use an awful lot is, "there's this lady I've worked with who's found this helpful. There's a lady I've worked with who's done this. And obviously 'this lady'..."

Would like to be able to disclose more about diagnosis and experience with clients in the future

(E:70:3) I do like to imagine that at some point in the future I'll be able to be more honest, but I don't think I'll be ready to do that yet.

Client knowing about participant's personal issues might make it difficult to focus on their own

(E:69:4) My flatmate is having CBT at the moment, and her therapist has had facial reconstructive surgery. And she says she finds it really difficult to think about the fact that there's almost this visual display that this woman has been through some shit...

(E:69:9) I was arguing with her – everyone's been through some shit. And she was like, "Yeah, but I would prefer not to think about the fact that she's been through some shit, because I want to think about *my* shit. And I feel like my shit sounds trivial, because she's been through other shit." And I feel like, you know, I would never want to get it wrong and make somebody feel that way, or try and relate and find that I wasn't relating.

Feels is still holding self together and doesn't want to add to another person's distress

(E:70:5) I very much feel like I haven't sorted my shit out yet, so I don't have a happy ending. I don't have a kind of like, "I was like that, this, this, this." I'm still very much just holding my shit together. So kind of, there's very much a risk that if I was to disclose that I'd be putting shit onto somebody, and that's obviously not what I want to do.

By contrast, likes the honesty of being able to discuss own diagnosis and experiences within hearing voices network

(E:68:3) I have done work with the Hearing Voices Network where I have disclosed, because that's part of the role. I've always felt that that's been more therapeutic and more helpful. And I've liked the role better because there's been more honesty in my part in it.

Because of experiences of being a service user, finds the structure of diagnosis unhelpful when working as a community psychiatric nurse in NHS

Diagnostic shorthand tells you nothing about a person's experiences

(E:64:13) when I was handed over my case notes from the previous person, she'd be like, "such and such is a paranoid schizophrenic who has" – and I've a lot of paranoid schizophrenics on my case notes, and I find that incredibly unhelpful. Cos I don't know, cos I've been trying to go through care plans to actually write what the problem is, and all that's transmitted to me is these diagnoses, which means absolutely nothing about what the person's going to be like, what their experiences are, what actually being unwell and what being well is like for them. How ill they get and how well they get and what the difference is, and what *they* think the difference is.

Patients used to a diagnostic response from mental health professionals find it hard to know what their own experiences are

(E:64:21) Half of them don't know themselves. They've been using mental health services for 40 years; and I'm like, "What happens when you're ill?" and they look at me and go, "... Well (*bewildered*) I'm psychotic." (*Laughs*) Great, that tells me *loads*. Like, "Do you hear voices, do you feel scared? Do people upset you, do you get cross with people? (Because) I don't know."

Without detailed understanding of an individual and their experiences it is impossible to tell from their diagnostic picture how well or unwell they might be

(E:66:1) it's so unhelpful. Like, not just for the individual, but in terms of communicating amongst professionals as well. Like, how am I supposed to know if somebody is in a bad way if I don't know what a bad way looks like for them, or what most days look like for them. We've got one guy at the moment, who's quite similar to me, in that he hears voices every day, sometimes quite a lot. And that's ok. Other people, if they hear voices once, that's pretty much, "Right, ok, shit. Things are going badly for you now" because that's a sign that things are getting out of control quite quickly." What do I know if I've just got a load of people in just one category on my caseload?

Dislikes 'us' and 'them' distinction in mental health, but recognises that some service users feel more comfortable with it

(E:69:3) whilst I'll complain to the end of the earth about the us and them, there are some of *them* that like it to be us and them.

Has been sectioned by NHS trust that she also works for, which shouldn't happen

(E:2:6) I work in my local mental health trust, where I receive services, where I shouldn't ever be hospitalised, but every time I get sectioned I get put there first before they manage to turf me out.

E15) In fourth, and most recent, breakdown was groomed by a psychic contact

Prior to most recent breakdown was coming off medication and was affected by the death of a colleague in the hearing voices movement

(E:74:1) he got killed... in February I think. It was really sad. And I think that was what started to make my brain not get everything quite right. And then I started to have- I got in touch with this psychic woman before Christmas to try and learn to use these kind of abilities, like more positively. I was trying to come off my meds. It was all at once actually. I was gradually reducing my meds from mid November.

Relationship with psychic contact began as positive, but became increasingly frightening

Flatmate told participant about the possibility of psychic contact

(E:77:4) I could sometimes see auras on people and stuff, and she (*flatmate*) knew a lot about that. She was into all of that stuff. And she was saying that you can really contact psychic people by really just like opening yourself up to it.

Never met psychic, but contacted her psychically

(E:77:1) I contacted her psychically, she wasn't a person who I met face to face. Which made other people, a little bit not believe me, but...

Got in contact with psychic who bolstered feelings of self worth in same way that man who sexually abused her as child had

(E:75:1) And then I got in contact with this psychic woman. Because that was my plan, I would come off the medication and learn to use my abilities for like good. And I contacted her and she was like, telling me that I could use my powers for good, that I was powerful and that if I could just train my powers... She was getting more, putting thoughts into my head. But like really good thoughts that were making me feel really good about myself. Grooming again. I think now with hindsight. I'm obviously a sucker for it.

Psychic contact enlisted participant for mission to rid the world of bad people

(E:77:7) she started putting these other thoughts in that we were these psychic warriors. And there's like these psychic warriors everywhere and I was going to be like chosen to be one of those because of one of my particular psychic powers. And we've got this responsibility, and it was all to do with like end of the main calendar in 2012, and this new world order, and we're all connected. (E:77:14) So I'm going to be this important warrior, and there's loads of other people, and so I have this important sense of belonging to this big organisation. And then she started with, "But then we have to overthrow all these bad people." And there are some people who are the warriors, and some people who are bad, and some people who are kind of neutral, and they're ok. But they're kind of dispensable. And so you have to protect the warriors and not worry so much about the dispensable ok people, and kill all the bad people. And then Brian got killed, and then off the back of that, she started- and obviously I was feeling angry and hurt.

Sectioned after being groomed by psychic contact

(E:78:1) I got very frightened, and I went to ask for some sleeping pills because I hadn't slept. And I guess - I don't know, from my notes it doesn't look like I actually told them what I was thinking. (E:78:5) So they put me anyway in Tollworth.

Started to believe that sister was a robot

(E:78:6) Then I thought my sister was a robot. I don't know where that came from.
(E:78:7) She lives in S****. So I flew out on my leave to S****. (E:80:1) I was going to find whoever had got my sister and probably strangle them. (E:80:4) anyway, I got there and my sister was fine and she came and picked me up from the airport and she wasn't a robot or a computer... (E:80:7) The next thing I knew, we were back at the airport and my dad was there with a bunch of Haloperidol and I was on a Business Class plane back home (*laughs*) without really knowing what the fuck had happened until I was back in the hospital...

E16) Voices have a meaning and a context that is individual, although not always understood

Experience of being sexually abused as child expressed in the content of voices

Experiences of sexual abuse followed by self-harm led to participant's psychosis
(E:18:1) (It) is kind of textbook. Get abused, self-harm, have an eating disorder, then get a psychotic disorder.

The voice of abuser appeared after break-up with boyfriend and threatened to jeopardise new friendships, mirroring threat of actual abuser to expose abuse to parents years before

(E:24:2) I was pretty much effectively, I'd got this life for myself. I'd got these cool friends, I was living in a flat share with people. I was popular, I had just had a boyfriend who had broken up with me actually, so that made me think that I wasn't that great – but I was kind of normal. Like I was another normal person like all the other normal people, and he (*voice of abuser*) was just like, "I can take all this away from you. I'm going to tell them. I'm going to tell them everything. They're going to know everything. You've been keeping this secret. You're sick." All the same things he was telling me before, "You like this, you like that. There's something wrong with you. You're crap at this, you're crap at that."

Experience of being raped by a friend expressed in the content of voices

(E:25:25) (*voice of friend who raped her*) asking for help, was there, and why did I let him down? Because I did let him down in the end because this thing happened...

Voices mean different things to different people

There is diversity of understanding about what voices are, including the concept that it may be an illness, although doesn't feel that adequately describes anyone she knows

(E:89:1) People seem to have really different experiences and a really different understanding of them. And you know, I don't think it's hugely far fetched to imagine some of them might have an illness. I can't give you any examples of people that I think actually have an illness.

Accepts trauma model interpretation of schizophrenia, which is often used in the Hearing Voices Network, but doesn't think that it applies to her

(E:89:5) I do buy into this whole theory, about trauma and dissociation and stuff that everyone's into in the Hearing Voices Network. And I think that's probably true for lots of people. And I can see how logically that may be true for me, but I can't see it;

it doesn't feel like it applies. And I see that in lots of other people. And I can see that in my clients as well. Like I think that's quite a good model for a lot of people.

Voices not directly related to experience may be forms of psychic communication from other people

Trauma model doesn't mean that voice hearers aren't also able to pick up voices psychically from elsewhere

(E:89:11) I also think maybe that some of the people who that model applies to, who've got that dissociative thing, actually part of that as a consequence of the trauma and dissociation, or whatever, that made them able to hear voices that might be parts of them, doesn't mean that they can't also hear other things that are important. That other people, you know, can't hear. I don't know, I have difficulty trying to explain my own experiences rather than trying to explain everyone else's as well.

Distinguishes psychic contact as a separate entity to voices

(E:84:1) she was very different from the voices. One of the things that infuriated me, is that everybody kept equating her with the voices. And I was like, "She's *nothing* like the voices. She's putting thoughts *right* into my head.

Sometimes hears voices which seem to be communications from people in other countries, which doesn't make sense, but then hearing voices *at all* doesn't make sense either

(E:84:5) I can sometimes hear voices and they'll be in India. And I'll know they're in India, and I'll know that it doesn't make sense that I can hear voices that come all the way from India, but then actually it doesn't make sense that I can hear voices *at all*. So, you know. If I feel like they're coming from India, I can't say that's exactly why. But that's where they are and I know that's where they're coming from...

Voices may be supernatural or come from a technological mechanism that participant does not understand

Participant feels she has no power over the voices, but somebody else does

(E:87:1) I have no power over it. If I had power over it, I could block it off when I want to go to bed and switch on in the morning. So I don't have any control over it. But I definitely have the sense that someone does. Who, or whatever, that someone is.

The voices are either supernatural or transmitted through advanced technology

(E:85:1) I think they're a mixture of something supernatural and something technological. But I don't exactly know how. But if I try and think they're completely technological that doesn't work. (E:86:1) I think the way they're transmitted to me is through some kind of advanced technology that I wouldn't know and understand.

Experiences voices talking about her, but not to her, suggesting there may be a higher technological power that filters voices that she needs to hear

(E:86:2) what I get is an awful lot of these voices who talk about me, but not to me. Or they talk about other things. (E:86:4) I think there's some kind of power, there's some kind agency I suppose, that's not in those voices, that's outside of those voices, that decides which snippets, or which things they say, that I need to hear. So that agent – whatever it is – is using this like really advanced technology to chose whatever it thinks is pertinent to me. Quite often I have absolutely no idea.

Something, I'll be like, "Oh I see why they're doing that, I see why I have to hear that."

Feels her experience with psychic, which led to most recent hospitalisation, may have been an attempt to find a more positive interpretation of voices than suffering from an illness

Episode involving psychic could be have been an attempt to find a more positive way of interpreting experiences than mental illness

(E:82:1) I guess it's from wanting to find a more positive interpretation of my experiences than mental illness. I still kind of feel that I would like to feel that I have some kind of special powers, or special abilities, or that I'm more able to connect with whatever else there is, than other people who can't hear voices and can't sense these things. (E:82:7) I was looking for something to make me feel better about myself I suppose. And something constructive.

In being part of a mental health system that she doesn't approve of, wanted to find a more positive approach to helping people

(E:82:9) I am very much in conflict at the moment, because I do work in mental health services, and I'm still unconvinced that by even taking my kind of very personal approach to mental health work, I'm still very conscious that I'm part of a system that I don't approve of. And it would be great if I could do work that would help people, not in that system. So this idea that I was developing, that I was setting up my own little psychic practice, where I could help people through my psychic powers was a lovely one that she really played on.

Despite 10 years of experiencing voices, participant is still frustrated, frightened and confused by them

Things happen in the space between people which is often hard to explain or make sense of

(E:88:1) I mean, I think there's lots of this stuff going on in the space between people anyway; everywhere. And I think people have different levels of awareness of that going on. And different interpretations when they do understand it. 'Cos I think my understanding is pretty limited, given that this has been happening for, you know. And I've been trying to work it out for a long time. I don't think I've got very far, which is frustrating.

Theory of voices becomes challenged when trying to describe it to someone else

(E:87:9) It's so strange, I feel that the ideas are quite well developed in my brain, but that when I start to explain them I don't have the exact vocabulary to explain what they are. But that's my working theory. It's changed before. If I had more information I'd have a better understanding...

Still frightened by voices and fears that others can hear them

(E:48:1) I still feel frightened when I hear them. It's still... 90 percent of the time quite frightening, which is *ridiculous* because it's been 10 years now. So it's *absolutely ridiculous* to find them frightening... But, I do. (E:48:5) I still think people might be able to hear them and that still puts me off. And they still muddle me up. They do. They still have quite a hold on me.

Feels she has changed a lot over the years, but relationship with voices has not changed as much as she would have liked

(E:48:7) I have changed a lot, you know, I have changed a lot. But a lot about them hasn't really changed. And a lot about my relationship with them hasn't really changed, in a way. Not as much as I would have liked. But they don't like that.

Participant F – Individual depiction

Now in his early forties, (F) had a mixed experience of psychotherapy. His first experience was CBT with a CPN, who (F) felt was nice enough, but didn't really know what she was doing, and that the work seemed rigid and simplistic. In hindsight he felt that CBT would have been helpful if there was a specific phobia or compulsion that he needed to address, but he also found it hard to remember what exactly happened because he was too out of it on medication at the time. Later, (F) began working with a psychoanalyst, but felt he was not interested in (F)'s experiences and didn't value his pain, and this made him feel like a thing. In turn, this reminded him of a feeling associated with past traumatic experiences, such as his difficult relationship with his mother, being bullied at school, and being treated as a sexual object by older men who took advantage of him when he was an adolescent. (F) had also had bad experiences in the neighbourhood where the psychoanalyst lived, and this seemed to provoke (F)'s voices, which was another incentive to end the work.

During this period (F) had attempted suicide a number of times, and there were repeated hospitalisations. There were times where being kept in hospital helped him to feel safe, and he sometimes enjoyed the camaraderie of other 'mentalists'. However, he also felt being diagnosed with paranoid schizophrenia and the medical treatment that followed it had taught him to see himself as biologically flawed, which reinforced his feeling of being a failure in life. He felt medical treatment taught him to regard his voices as white noise, rather than meaningful, so all he could do was attempt to suppress this noise. However, this seemed to have the consequence that he feared the voices even more.

Throughout his thirties (F) began to develop his poetry writing, and this led to performing his work publicly. He also developed friendships with people who were active in the recovery movement, and began to think that his voices might be meaningful. However, he was wary of trying to explore this meaning psychotherapy. After taking part in a film project which explored some of his experiences, he emboldened to try and make a change to his life. However, he felt unable to make the kind of changes he wanted to make, and, combined with the stress of a failed relationship, he had a breakdown and attempted suicide. This led to a breakthrough, and after a period in hospital, he was referred by his psychiatrist to a Personal Construct (PC) therapist. (F) felt his experiences of psychosis were validated in this relationship, and he also felt respected. In this therapy, (F) felt encouraged to explore the content of his symptoms, and this led to him making links between traumatic experiences, such as difficult relationship with his mother, being bullied at school, and confusing early sexual experiences, and voices and hallucinations. This process has also helped him to start naming some of the voices and the personalities that accompany them. In symptoms as detailed aspects of self, (F) also found that some of the voices/personalities were comforting and supportive.

Making these kinds of connections seems to have helped (F) regard his internal life less as an enemy, and rather, an important aspect of himself that he can continue to develop. (F) also felt that in addressing his conflicted sexuality, he now feels less self-loathing, and his voices have become kinder, and appear less often. At the time of interview, (F) was planning to begin working with an art therapist, and to return to university.

F1) experienced difficulties in childhood

Felt wasn't allowed to express emotion in family

(F:42:1) I always felt I was never allowed to have emotions. I wasn't allowed to be miserable, I wasn't allowed to be angry, I wasn't allowed... to be silly. I just had to be nice - sit in my corner and be nice. And I'm not a nice boy. I'm a nice bloke, I'll go the extra mile for my friends and I tried to be kind to people, but I'm a mouthy, opinionated person and I'm also quite emotional.

Difficult relationship with mother

Uneasy relationship with mother because she needed everything to be perfect

(F:41:1) I always had a very uneasy relationship with my mother, I didn't really understand what was going on because I was terribly young but she never had very much time for me. She wasn't a very nice person and she wanted a sort of perfect middle class life. Everything had to be nice. You know she was a housewife, you know the house had to be perfect, the garden had to be perfect, there had to be perfect meals... And I was always pissed off and unhappy.

Participant felt that mother didn't love him/wasn't able to show love

(F:42:5) I can remember my mother hugging me precisely once in my entire life. Properly. And that was out of pity. You know, she was a bitch. I mean to be honest, when I was 14, I was sitting in the living room reading my book, and she turned to me and she said, "J**", sometimes I could almost love you." (F:43:1) She meant she didn't love me. She never loved me.

Experienced feeling of mother holding him in contempt

(F:43:1) She always felt I was a fool. She didn't understand me. I can show you a picture of her. (*Gets out picture*) That's my mum and me. Look at the expression on her face when she's looking at me... (F:44:1) Contempt. She didn't like me.... She just didn't like me. She didn't get me. She always thought I was gay. She was a woman who was given to making nasty little remarks under her breath and I heard them, they registered on me.

Unable to communicate with mother

(F:44:10) she never talked to me at all. I never had a single conversation with her.

Mother had problems that had an impact on participant's relationship with her

Mother was from sheltered conservative background in Rhodesia, and was bullied at boarding school

(F:46:6) You know, she grew up on a farm in the middle of Africa, knowing her mum and her dad and her younger sister and 'the boys', as they called black workers over there - 'the boys'. You know she knew nobody, very restricted life, then she went to boarding school where I think she was bullied, I'm not sure but I got the impression that she wasn't happy at school. And then, I think she was always a sort of quiet, dreamy, she loved poetry and books and stuff.

After meeting participant's father and moving to UK, felt alienated and had difficulty in making friends because her background was frowned upon

(F:46:11) She went to the university of Rhodesia to study English. (F:47:1) She met my dad and he was a post grad there, travelling through Africa, and he probably

seemed exotic and different and interesting. And they were living together for a while, and then they got married basically 'cos they were living together and that was frowned upon by like her parents... (F:48:1) They went back to England and I think she found it very difficult to get on with English people, 'cos she was from Rhodesia and she was moving in quite left wing circles and they all sort of condemned - and rightly so in my opinion - the white farmers. She found it very difficult to make friends. She only had a handful of friends. I think she was deeply unhappy.

F2) Had psychotic and dissociative experiences as a child

Experience of hallucinations aged 7 and 11

(F:1:6) The way I conceptualise my condition is that I have a dissociative condition. I've always had problems with reality. I can remember having hallucinations about God when I was 7 years old. I've always had dissociative episodes, throughout my entire life. (F:6:1) I can remember one incident very clearly when I saw when I saw the light when I was 11 years old, and I was terrified. I can't really explain it, it just, I was at school and I saw the light - it was a psychotic experience - I could see everything really, really clearly and everything was lit up.

Sensation of being shaken awake as a child

(F:159:4) as far back as I can remember I've had this experience where I feel like I'm waking up, I'll be walking along and I feel like I've just been shook awake and everything looks completely foreign and alien to me. Like when you wake up really quickly and everything looks weird. And as far back as I can remember I've had that experience about once a week or so.

F3) Experienced trauma in childhood

Moved to an alien culture aged 11 and didn't fit in

Was a year younger than rest of year and experienced culture shock

(F:23:1) I've got a lot of anger towards my parents, *a lot* of anger. My dad was a teacher, an academic, and he took me to the other side of the world, you know, like 6,000 miles away, dumped me into a completely foreign culture at the age of 11. You start secondary school at 11 here, but it was 12 over there, so everybody was a year older than me anyway, which is a lot to deal with anyway, when you're a kid. And they had a completely different culture, they talk like this all the time (*Rhodesian accent*). They've got this very strong accent and they talk in a completely different dialect. (*Return to own voice*) Like they've got different words, I didn't even understand what people were saying to me for about 2 years. It's completely ugly. It was like a complete culture shock.

Didn't fit into sporty, physical culture of school

(F:24:1) I was quite a shy, sensitive, withdrawn, bookish child and they just thought I was a nerd. They were all running around playing rugby and I never liked competitive sports, the only thing they respected was strength. And I'm not physically strong.

Parents' politics alienated participant from his peers at school

(F:24:4) I was brought up by communists who went over to Zimbabwe to help the revolution. And they were Rhodesians who'd just fought a war and some of them had lost, like- I can look back on it and see why they hated me. You know, they'd lost fathers and brothers in the war and I was saying, "Well Viva La Revolution. This is the right thing to do. Mugabe is great." Obviously they hated me.

Was bullied at school

Was a fey child and regularly beaten up by peers

(F:22:1) I was always a fey kid. (*S African accent*) "Are you a moof, are you a homosexual?! Are you a girl or a boy?" (*Effeminate voice*) "Why don't you find out darling – Ow!!!" You know, I did live with that for 6 years... (F:22:4 – F:22:9) *Participant describes the macho culture of peers* (F:22:9) And I was swanning around in boots, tight red trousers, blouses, long dangly earrings with a Mohican at the age of 15. (F:22:12) I hated them and they hated me. And they were a lot bigger than me so I got my head kicked in regularly (*laughs*).

As child, was frightened of men because of being regularly beaten up

(F:50:1) I was very mixed up when I was a kid. I was frightened of men, because the only experience I had with men was them hitting me.

Trauma of bullying mirrored mother's contempt

(F:90:1) it's a combination of my mother thinking I was a fool and all the kids at school hating me. I mean it was 6 years of everyone I met treating me with complete contempt. Just despising me.

F4) Confusion over sexual identity in childhood and adolescence

Confusion over sexuality started at 10 years of age

First sexual feelings provoked by Rambo, aged 10

(F:151:1) The first sexual experience I had was with a review of Rambo. Right - it was in the back of a Penguin book that my parents had. And I used to go into the room and read it and it said "Bare bottomed naked." And I got this incredible thrill out of reading "bare bottomed", and I didn't know why.

Early exposure to pornography written from the point of view of a woman played into sexuality confusion

(F:139:1) my dad's collection of pornography, which I discovered when I was 10 I think, was all things like Emanuelle and Delta of Venus by Anais Nin and Deep Throat, and all this stuff. And it was all like written from the point of view of a woman, and it really confused me. I mean I was looking for my clitoris when I was 11...

Sexual experimentation at 11 years old with older boy

(F:26:2) He was gay and we had a kind of thing. He was 2 years older than me, he never said but I was 11 he was 13 and I think he had to change schools 'cos he got nicked for being gay...

As a minor, was used for sex by older men

Underage when had first boyfriend who was much older and who offered participant for sex with his friends

(F:51:1) I had my first boyfriend when I was 15, who was an older guy, T***, who was the manager of a nightclub... (F:51:3) And he kind of groomed me. You know he was attracted to me; I was a fey kid. And he used to let me in for free and buy me beer and get me taxis home and take me to parties and buy me clothes, and you know. I didn't love him, but he was nice. (F:140:1) some of T***'s friends (*had sex with participant*), 'cos he passed me around.

Raped by a man when 15 years old

(F:52:1) I was raped when I was 15. (F:53:2) I was at a party, I was very drunk and very stoned and this guy who was notorious on the scene was saying he would look after me, and he raped me. While I was throwing up. (F:56:1) Wanna know the sickest things about it?... I enjoyed it... I slept with him again.

Sexual relationship with mixed couple who he shared house with, aged 18

(F:18:1) it was a very weird relationship because he was going out with a girl that I was in love with and they were like banging, we were sharing a house and I could hear them having sex in the next room and shit and I was in love with both of them and then I was having sex with him and getting off with her and we were all sharing the house and living in a squat together.

Confusion between violence and erotic feelings

Bullied by friend who he was also sexually attracted to

(F:27:1) he was supposed to be my mate, 'cos we hung round, but he had complete contempt for me. I was kind of fascinated by him 'cos he was a good looking guy, he was very handsome and being like that, obviously I was quite attracted to him. And he was very strong-willed. He was like an Alpha Male and he was like the leader of our little gang. (F:27:8) he came over to England when I was 18 and he lived in the squat with us and then he came up to L***** with me when I left there and lived in my family house and really took great pleasure in deliberately, when I was having a breakdown in giving me a lot of shit. (F:28:13) And the trouble is, I was so ill I couldn't fight out and he just crushed me. (F:100:9) He never had any respect for me.

First time had sex with male housemate was after being beaten up

(F:20:1) It was completely fucked up. I mean the first time we had sex it was the night I got beaten up. (F:20:4) I got into a fight and I came home with one of my contact lenses knocked out and bruises all over my face and he went down on me for the first time. You know – timing.

Links between sexuality and low self-esteem

Low self esteem meant that participant accepted offers of sex from anyone

(F:56:3) I'm just a girl who can't say no, I've never - anyone who shows the slightest interest in me I'll go to bed with them. I was told for six years at school that I was ugly and stupid - and that kind of sticks.

Felt incapable of relationships because of fear of both men and women

(F:140:7) an older woman, P***, was the first woman I ever slept with. There were people who were interested in me, but I was so fucked up that I couldn't have a

relationship with anybody. Because I covered up my messed up-ness and insecurity by being very mouthy and nasty to people. (F:141:1) I was frightened of everybody. I was frightened of men, I was frightened of women.

F5) Experienced first breakdown in late teens

Mother died and then was alone in new country, aged 17

(F:39:1) my mum died when I was 17, just before I came back. (F:39:4) I was going to come back here and go to 6th form college and try and get into university. And then my mum died. I spent a year and a half living in L***** in a house by myself, knowing only my grandmother and my aunt and uncle and their three kids and some people in London.

Sense of liberation after moving to London

(F:39:9) Best days of my life actually. Went down for the holidays, living in a shared house in Tottenham, being a KP - kitchen porter - washing pots, and we were all doing shitty jobs, cleaning and through temp agencies and just getting drunk and stoned and having parties, it was great. First time I ever had real friends.

Breakdown began in first year of university

Read English at university but became disillusioned

(F:32:3) They gave us 'Waiting for Godot' to read. You know by Samuel Beckett. They said 'After Waiting for Godot, is there any future for English literature?' (F:33:1) I was into the you know the Situationists – Guy Debord and Raoul Vaneigem - I was reading a lot of that stuff, I was reading a lot of the Frankfurt School, Theodor Adorno. The culture industry, which says culture's a big fucking con. It's just another way of the ruling class fooling people. And I really believed that, I thought it was all just a fucking con, so it seemed absolutely pointless doing English. (F:33:7) I just fucked up completely. All I did was suck N****'s cock and take a lot of speed, and drink a lot.

Dropped out in third term and couldn't get out of bed for 3 months

(F:34:1) In my third term there, I moved out of F***** Lane into a bedsit. I was still in N***** but I'd stopped going to university, and I'd just cut myself off from everybody except for B*** who was my mate... (F:34:4) And I didn't get out of bed for 3 months, I literally just lay in bed, and God started talking to me. (F:29:1) I was having a breakdown. I was completely withdrawn, couldn't look after myself...

Began hearing the voice of god and the devil

Felt suicidal when hearing voice of God and Devil saying that the world had died

(F:36:1) When God talks to you, you don't argue... I just believed it. I knew it. (F:37:1) it's like somebody tells you that everybody on the planet that you see is the living dead. The devil's in control of the world - the devil was talking to me as well... I just wanted to die.

Received messages from God that felt he had to decode

(F:38:3) I thought, right, what God told me to do was to write the Book of Lies and these were God's last messages to his creation, and they were buried in songs and in books and my job was to collect them all and to put them together into the Book of

Lies. And a lot of the stuff that was in punk music was like God's last message to his creation. And one of those messages was No Future (*Sex Pistols* lyric). (F:14:4) for about 5 years I firmly believed that The Rapture had already occurred in 1977 and that everybody - all the people who were good had been taken up to heaven already and the devil was in control of the world and we were all the living dead. (F:15:2) I was listening to a lot of punk and reggae and taking it very seriously, and 1977 was the year of punk, and it was also the year that Elvis Presley died and I thought Elvis Presley had ascended to heaven and taken all of the good people with him. The Rapture had already occurred.

Rationalised that voices of childhood bullies must indicate ability to travel through time

(F:1:9) When I had my psychotic breakdown, God was talking to me, the devil was talking to me, and various people inside my head were talking to me, as well as me hearing the voices of the children who bullied me at school, and people from my past. Which at the time I understood as me travelling in time. I thought that what I was thinking in the present was affecting what had happened to me in the past.

Hallucinogenic drugs exacerbated a fragile state of mind

(F:30:6) I was smoking a lot of weed, doing a lot of speed, doing a lot of acid and mushrooms and stuff. Doing hallucinogenics is not a good idea for somebody with a fragile mind. It really fucked me up.

Fragile state of mind compounded by confusing sexual relationships

(F:31:1) basically I got to U*** in a very fragile state of mind, having come out of this relationship with (*male and female couple that participant was having sexual relationship with, as well as living with childhood bully*) Nobody knew me. I was trying to reinvent myself... I fell in love with this bloke called N***... and we were in this weird - *another* - weird triangular relationship with me, N**** and E**** (*N****'s girlfriend*), and we were all shagging each other.

F6) Period of stability before second breakdown in early 20s

After first breakdown was living with girlfriend and coping with psychosis

(F:116:1) I was living with psychosis. It had sort of got a bit better, but I was still psychotic. I was able to function to some extent and I'd got into this relationship and I was living with her. And her grandfather was labelled schizophrenic and I think she sort of recognised the symptoms. And got me to go to her GP, Dr C****, who's a very good GP, a very nice man and - even though he believes in the medical model and is a bit too quick to prescribe medication. He put me on Sulpiride and antidepressants.

Second breakdown triggered when relationship with girlfriend ended

(F:116:1 – F:116:7) *Participant was relatively settled for first 4 years after first breakdown and was living with a girlfriend who had facilitated intervention from GP who administered antipsychotic medication.* (F:116:7) (However, girlfriend at the time) left me and I was going to be homeless and my life was a piece of shit, so I made a very serious suicide attempt and after that they took me on to the ward. I jumped off a 40 foot bridge in front of oncoming traffic and broke both my legs and my back...

F7) Receiving schizophrenia diagnosis came 4 years after initial breakdown and has been a negative experience

Didn't receive diagnosis until serious suicide attempt, 4 years after first breakdown

(F:1:1) as far as I can understand it, I had a complete breakdown in 1990, and had psychotic symptoms for years after. I wasn't diagnosed 'til 1994, when I made a very serious suicide attempt and ended up in the system. They then diagnosed me with clinical depression and paranoid schizophrenia.

The schizophrenia diagnosis is meaningless, and is a negative label

(F:96:1) I reject the label of paranoid schizophrenia that I've been given, I don't think it means anything. It's not a biological flaw. (F:1:5) I think it's a negative label.

F8) Medical treatment dominated by medication

Antipsychotic medication had little impact on voices

Hospital treatment involved medication only which didn't work and made participant feel zombified

(F:117:1) They put me on a ward for 6 months... I wanted to leave but they said they'd section me if I tried. They put me on all sorts of different medications, none of them worked and I was on a depot for a while, I ended up on Clozaril, which was just a chemical cosh. It just zombified me completely.

Psychiatrist wouldn't take participant off Clozaril, despite having little effect on hearing voices

(F:119:5) They don't give it to you unless everything else fails, and they won't take you off it once you're on it. And I was trying to come off it, 'cos it wasn't working... (F:119:9) and my psychiatrist wouldn't take me off it for like 3 or 4 years.

Antipsychotic medication had serious side effects

Clozapine anti psychotic medication had serious side effects

(F:117:4) I was a complete mess when I was on that drug... It's an evil drug you shouldn't prescribe it to anybody. It can kill you for fuck's sake! I used to have to go for a blood test every two weeks for 15 years to make sure my immune system didn't fail. (F:119:1) I had no energy I was sleeping the whole time. I was sleeping sort of 10, 12 hours a day. I got fat, I dribbled all the time. I had retrograde ejaculation, I developed epilepsy because of it. It *really* fucked me up. And it didn't work either.

Participant self-medicated with alcohol which was more effective at reducing voices than medication

(F:119:7) I was just drinking all the time to try and stop the voices – 'cos that's the only thing that's ever worked is booze...

Participant met resistance trying to come off medication

Psychiatrist initially resisted participant coming off Clozaril, but facilitated this after pressure from family

(F:120:1) She thought everything would get worse and there was no point trying me on anything else. But after I had the breakdown 18 months ago, and also because my

family got involved and they're all quite middle (class) - they're all doctors, and you know quite middle class - and 'cos they came on board, I think she listened to them to be honest. (F:120:7) She said I was right to say I wanted to come off it and she would listen to her patients more in future and she's written a note in my file to say I'm never to be given that drug again.

Coming off Clozaril helped participant to feel himself again
(F:118:1) I feel myself again.

New anti psychotic is better than Clozaril, but trying to come off medication all together

(F:121:1) I'm on Amisulpiride now. Still on an anti psychotic. (F:122:9) I'm coming off- I was on Epalim, to control the fitting which was caused by Clozaril, Sodium Valproate, which is also a mood stabiliser. And it's been fucking my sex life up, 'cos it kills your sex drive, which is like the last thing I need, so I'm coming off that at the moment. And I've reduced my antidepressant by half and I'm hoping eventually to be meds free, but that really does depend on the psychiatrists.

Relationships with psychiatrists are no use unless you are able to talk
High turnover of locum psychiatrists who only enquire about medical issues feels useless

(F:122:1) I've had locums for the last year and all they ever - I mean I go to the ward and see them - and all they ever do is say, "Are you still on your meds? Do you have any suicidal thoughts? See you in 3 months." You know - I mean they're fucking useless, psychiatrists. Unless you get one who actually talks to you.

Talking input has been helpful

(F:122:5) the last one I saw (*psychiatrist*) was ok, I had a care plan assessment and she, Dr K****, she's quite nice. And I met up with her and my CPN J***, who's lovely, and my care worker from Network for Change - which is a local support group - L****, and my uncle. I brought him along as well and we had a good chat, talked over everything...

F9) Where therapy has been unhelpful

Cbt therapy was not helpful

Felt that CBT therapist didn't know what she was doing

(F:142:1) It was somebody who was doing CBT for the first time and she came round and did a series of assessments on me and did some CBT work with me but it wasn't of any use to me at all. (F:146:1) She was alright, she seemed a nice enough person. But she just didn't really seem to know what she was doing.

Participant felt that CBT not able to deal with his problems

(F:81:1) I think CBT can help people with, like OCD, or phobias, or something like that. My problems are different from that. Problems - my *condition* is different from that.

CBT could have helped with vertigo phobia, but this was not worked on
(F:145:1) I just didn't get anything out of it. I mean I think CBT can be, like I said, useful if you've got like behavioural problems - OCD or phobias, social phobias, scared of something. You know I've got really bad vertigo because of the bridge incident and stuff like that, but we didn't really work on that. If I could have addressed that at the time, that might have helped.

Being heavily medicated made it difficult to engage with therapy

(F:143:1) I can't remember it now (*CBT therapy 12 years ago*). To be honest it's years ago and I was pretty zombified on drugs at the time.

Not feeling respected by therapist

Psychodynamic therapist reminded participant of a teacher

(F:146:2) I went to a private therapist for about 3 months, about 3 years ago.

(F:149:1) And I told him some stuff like pornography things and he just didn't, like I said my first sexual experiences were with books and he said, "Well how does that make you feel?" You know he didn't help me and he just reminded me of a teacher.

(F:151:10) he was professional and not caring, so I didn't like him and I didn't continue the therapy.

Experience of being treated like a thing in therapy mirrored trauma associated with being treated like a thing in past

(F:154:1) I didn't feel like he treated me like a human being. He didn't value my pain, you know. And I've been, I've been turned into a thing by people before...

(F:156:1) when I was in Rhodesia/Zimbabwe, they treated me like a thing, and then when I was having my breakdown people treated me like a thing. D**** treated me like a thing, R*** treated me like a thing, you know he came round every 3 or 4 months to get his cock sucked and then fucked off again and only ever told me he loved me when he was very, very drunk. And N*** my boyfriend at university, towards the end he treated me like a thing.

Negative associations with therapy location provoked voices

(F:148:1) he lived in E*****, just down the road from where my cousins used to live, and I used to have this... my voices told me that I had abused one of my cousins, which was horrible and obviously not true. But you know, we used to play together and sort of rub, I was 17, she was 11 and you know we sort of used to roll around on the floor and that, and tickle each other and my voices told me that I abused her. And because my aunt and uncle and my cousins lived in that area, I kept getting voices when I was going to these therapy sessions. So that was very difficult for me.

F10) Recent breakdown became a breakthrough

Breakdown was compounded by unaddressed voices, side effects of medication, and breakdown of relationship

Lack of efficacy and side effects of Clozaril, and breakdown of relationship with a woman contributed to breakdown

(F:60:1) Everything went wrong in my life. Major thing was I was on Clozaril and it wasn't working. I was hearing a lot of voices and I felt awful. I was fat and dribbling, I had retrograde ejaculation from it... (F:60:5) I had epilepsy from it - I was fitting a

lot. I had been through a very bad relationship with a lady who basically just used me for sex. You know, she was living with somebody, and she'd come round, fucking me, having a bit of a chat and going home to *him*. And then she dumped me and didn't explain why. I was very sexually confused.

Voices became overpoweringly negative in their allusion to sexuality and participant reached conclusion that they were right

(F:58:1) I had another breakdown about, in December the year before last, when I just had a complete breakdown. (F:70:4) I just woke up one morning and the voices in my head were just screaming, "You're a wanker, you're a wanker, you're a wanker, you're a wanker!!!" (F:75:1) And the trouble was I woke up one morning and I was half asleep and I agreed with them. I said, "Ok yeah I am a wanker." And I just thought, "I can't fucking live like this." (F:76:1) (I felt) that I was pathetic. Just useless. Not a real man...

Stopping smoking affected Clozaril uptake and voices increased

(F:69:7) the other thing that fucked me up was I was trying to stop smoking and that has an effect on the Clozaril, but I didn't realise that at the time, so that really fucked me up. (F:70:1) It affects the way it's taken up. And I was hearing a lot of voices.

Breakdown culminated in suicide attempt and return to psychiatric hospital

(F:67:2) I tried to commit suicide because I wanted to die, 'cos I honestly just was sitting here in this room and thought I can't go on like this, I can't live through another day. (F:58:2) I cut my wrists very badly and nearly died and ended up back in hospital. (F:59:1) 15 stitches, went through an artery, nearly bled to death.

Recent hospital admission was a good experience

In hospital, felt better when taken off Clozaril

(F:78:5) I had 2 full on fits while I was in hospital, and they put me on Sodium Valproate to control the fitting; so I haven't had a fit since February because of it. They took me off Clozaril and put me on Amisulperide, which is treating me pretty well.

Found self in a ward with old friends, and life got better

(F:78:8) I had a good time on the ward actually, 'cos my friend B**, who's adopted me as her older brother, and S**** was on the ward and, you know, she calls me her gay husband, we're really close. And my friend J**** was there, my friend K**** was there, we had a really good, you know *quite* a good time on the ward. I just bounced back, I hit rock bottom and came up smiling, and life has just got better since then.

F11) Where therapy has been helpful

Experiencing a human connection with therapist and feeling respected

Getting on with personal construct therapist was key to the therapy

(F:81:3) after I came out of hospital my psychiatrist put me in touch with an NHS therapist and I did six months of personal construct therapy with him. (F:82:1) I got on with him, which I think is the key to therapy...

Human connection with personal construct therapist

(F:152:1) with G***, who did the personal construct therapy, I felt that there was a connection there, and I felt he respected me... And actually when he wrote the final assessment when we'd finished the therapy, he said that he'd enjoyed working with me and that it was interesting. So I felt like there was a human connection there...

(F:168:3) what you need is engagement with real people. Somebody who'll just take the time. Ok, maybe you might be a difficult person. But we all deserve a bit of love and respect. 'Ohgunto' – 'I am because we are.' (In) Xosa.

Feeling affirmed by personal construct therapist

(F:85:4) I'm not good at competitive sport and that's the only thing that was respected in Rhodesian culture, was strength. I've always felt like a failure. And he said, "You are incredibly tough, because you've gone through what you've gone through and you're still here, despite 3 serious suicide attempts and 20 years in the wilderness. You're still walking and talking and you've got friends. Most people would be just completely crushed by what you've been through." And that was a really positive thing for me to hear.

Understanding issues within family

Understanding mother's difficult life was helpful

(F:46:3) One of the things that therapy was very helpful for me was trying to understand her, 'cos my therapist, G***, said you've got to try and understand your parents in their family relationships. And I've tried to think of my mum like this, and she had a very difficult life.

Connecting mother's issues with love with own need to be looked after

(F:57:1) my mum didn't love me. I've got this huge need inside me for someone to look after me. I'm looking, but it's something I've worked out recently, you know you can't ask for someone else to make it all better. But for the last 40 years, 30 years, I've been looking for somebody else to make it all better for me. But I've realised recently it's just not going to happen.

Building a more positive picture of self

Working on negative self-image

(F:88:1) I've always thought that I was completely unattractive and weak and pathetic and I'm working on that.

Developing a portrait of self as might be depicted by sympathetic friend

(F:86:1) the first thing he asked me to do was write a portrait of myself as told by a sympathetic friend. (F:86:5) So I wrote a history of you know what I'd gone through and we worked from there. (F:87:1) the idea is that you build up a picture of yourself and then you try to look at it from a different angle and see if the emotional responses you've grown up with are still valid. Because you form these ideas about yourself and other people when you're very young and you don't realise what you're doing.

Understanding voices helped decrease their power and frequency

Therapy happened at the right time, when participant was ready understand voices rather than attempting to silence them

(F:124:1) G***, was a really good therapist, he really helped me. And I was doing a lot of work myself, you know thinking things through, trying to understand it, and talking to my voices, instead of just trying to get them to shut up, actually.

Rather than thinking of voices as psychological flaw, reconceptualised them as aspects of self

(F:89:1) the major thing was I reconceptualised my voices. After experiencing them through the medical model for 20 years; I thought that they were just sort of noise in my head and I was psychologically flawed. I read a lot and R** encouraged me to talk about this a lot as well, I conceptualised it as dis-association and understood that I have these people in my head who talk to me - Jay and Kay and Jonathan and Panic and God and the Devil and all the people who bullied me - I conceptualised it as that.

Therapy helped to create definition and personality in what had previously been experienced as white noise

(F:111:1) It was just noise in my head, I didn't understand it. (F:102:1) I didn't conceptualise them properly. I just heard them - they came out sometimes. (F:103:1) I could hear their voices talking to me, but I didn't conceptualise them as... I mean I recognised God and the devil 'cos God talks to you and I can always recognise the devil because he talks to me with implacable hatred. He hisses at me like a bed of snakes, it's horrible. But I didn't understand Jay and Kay and Panic and Jonathan, but then I conceptualised it as dissociation and it made sense to me.

Communicating with voices helps them respond to conscious wishes

(F:124:4) I mean I've got to the point now where Kay will come to me and sing to me and then I'll say, "Right I've got to do something now Kay." And he will bow gracefully and go away.

Therapy has reduced frequency of negative/attacking voices

(F:92:1) I still sometimes hear the voices of the kids who bullied me at school; hated me at school. (F:93:1) (But) A lot less.

Therapy eradicated commentating self-critical thoughts

(F:89:7) I stopped having bad thoughts through the therapy and through working on myself. 'Cos for years if I did anything wrong, like I was making a cup of coffee and I forgot to put the coffee in the cup or forgot to put the kettle on, I'd beat myself up half an hour afterwards saying, "You're pathetic and stupid." And I just sort of took a step back one day and said it doesn't matter, everyone makes mistakes. And to be honest overnight the bad thoughts just went away.

Therapy allows space to talk about trauma which is related to mental health problems

Trauma underlying mental health problems needs to be talked about

(F:158:3) Every mentalist I know is incredibly traumatised, either by their parents, or their school, or they're ex-squaddies. Every ex-squaddy I know is completely fucking mentalist. They're all alcoholics and druggies and completely fucked up. And you need therapy, you need someone to talk to.

Therapy helps relieve trauma, but you need to do it at the right time

(F:164:1) I just think therapy's very, very beneficial to people. I wanna make that very clear. (F:158:1) I mean you have to be in the right place at the right time to do it, but I think that talking about your problems, the trauma you've experienced (is important).

Participant feels trauma caused his split personalities and psychotic breakdown

(F:97:1) I think I've got a tendency to disassociate and due to the trauma that I went through, I had these various split personalities. I had a psychotic breakdown when I was 20 and I've never really recovered from it.

More able to be more open about sexuality since beginning recent therapy

(F:61:1) I never talked about it for years. I felt very mixed up about it. I only came out as a bisexual person about 9 months ago and I consider myself to be queer. Not gay as in happy, but queer as in fuck you! I'm bisexual but most happy with men. (F:63:1) coming out's made a great deal of difference to that because I feel I can perv and I don't feel filthy about it. You know, I can look at - I like muscles you know. And I like male bodies.

After good experience of 6 month time-limited personal construct therapy on nhs now paying for private art therapy

(F:137:1) I'm going back to art therapy, privately. I'm starting that next week.
(F:138:1) there were a lot of things that I wanted to talk about to G*** that I didn't get a chance to... J*** D*****. I never talked about the fact that I was fucked up by my dad's pornography collection. I never talked about that. I wanna talk about that to my art therapist. You know, 11 year olds shouldn't read Anais Nin It's not a good idea...

F12) After long period of being afraid of 'schizophrenic symptoms' now understands them as related to traumatic experience

The sensation of time travel was actually suppressed traumatic memories returning

(F:5:1) I think I dissociated a lot when I was a child, and what it was, was memories coming back that I had suppressed for years, and I was experiencing it as me affecting the past, where it was just memories coming back.

Becoming open about sexuality has reduced persecutory god and devil voices

(F:134:1) it's the whole thing about being able to fancy men, is the difference, it's like now I can walk down the street and think, "He's cute or he's got a nice bum", and not feel guilty about it. I mean my God is a very Old Testament God and he doesn't like me being queer. God and the Devil give me a lot of grief about it. You know, 'thou shalt not lie with a man as with a woman, it is an abomination' – Leviticus. You know, and he's always tormented me about that.

The voice of god cannot be real, because medication blocks it out

(F:96:3) God's always troubled me, I've always been, felt very - I don't believe in God, I don't think there is a God, I know there isn't a God because when they give me the tablets he stops talking to me.

When god talks, it feels like more a sense of knowing something, than actually hearing a voice

(F:13:3) I just know things - it's like when God talks to me he doesn't *talk* to me, he just leaves messages in my head and I know they're true. It's not like hearing a voice, it's knowing something.

Distinct, mostly benign and supportive voices have emerged from the white noise, which represent aspects of participant

Blocked out multiple personalities in the past because wasn't able to experience them in the right way

(F:5:4) I always had multiple personalities and I blocked out a lot of them for a long time and it was a process of re-integration. I just didn't experience it in the right way.

Jay is a 7-year-old boy who is calming

(F:7:2) I hear the voice of Jay who's 7 years old and very, very quiet and calm. He doesn't really talk to me he just comes as a presence and he calms me down.

Kay is an 11-year-old gay prophet who expresses participant's creative side

(F:7:4) I hear Kay who's 11 years old and who's gay and who's a prophet who like sings to me. And he talks to me about anarchy and, I mean he makes me cry with joy, because what he sings to me about is so beautiful about the way the world could be if we lived in a perfect society, and he really *believes* it. (F:110:1) He looks like a phoenix. He's got wings of fire, he's bright yellow, he's bright light... (F:109:2) Kay is like my creative side...

Jonathan is participant's 14-year-old bullied self and expresses rational side

(F:104:1) Jonathan used to be called Jonno, which is what they called me at school, and he's like 14 years old and he's the sort of part of me that was really badly bullied. I always hated being called Jonno and *he* hated being called Jonno, so I had this conversation with him and I renamed him Jonathan, which is like my birth name. And he's a lot happier now, he's a lot stronger. (F:8:4) We had a long conversation and he's happier now, he's stronger.

Panic is in his late teens and expresses participant's anger

(F:9:1) I hear the voice of Panic who's about 18, 19. And he's very angry and he comes out of me sometimes when I'm stressed or pissed off, and he's very aggressive. (F:125:2) I have a difficult relationship with Panic because I'm an angry person. I'm angry about the way I've been treated by other people and I'm angry because of the society I live in. And Panic is my anger, but it's ritualised. I mean Panic comes and I bang on Crass and jump around the flat and get pissed and he goes away. I mean sometimes he comes out when I'm talking to people and I scare people, 'cos my eyes go funny and I start getting into people's faces.

Viva is an older, maternal healing voice who feels comforting

(F:9:3) I've heard a new voice in the last 3 weeks. It's an older lady called Viva and she's sort of turquoise blue and made out of stained glass, and she's very comforting. (F:11:3) She's quite maternal. I had a very dodgy relationship with my real mother, I didn't get on with her, she didn't get on with me. I've always been looking for a maternal figure and Viva is my mum. (F:13:2) I was half asleep lying in bed and I wasn't feeling very well and I just could see her and I knew her name.

Conversations with voices are experienced as thoughts, rather than external voices
(F:106:1-F:109:1) *Participant experiences conversation with the Jonathan voice as more of a thought conversation than conversation with external voices. In the thought conversation, Participant F does not know what the Jonathan voice will say next/experiences no conscious agency over the voice.*

Trauma of bullying has moved from realm of hearing voices to dreams, which feels like a healing process

(F:16:4) I think my unconscious, my subconscious, however you conceptualise it, is actually healing at the moment 'cos I've been having all these dreams about people who bullied me and I've been able to tell them to fuck off in my dreams. (F:17:1)

F13) Other recovery factors

Developing as writer and being paid to perform work has built self-confidence

(F:101:1) one of the other things that's been very healing for me is, like I'm a writer, I write poetry and I'm getting paid for my gigs now and people like what I do. And I find that very important that I've actually achieved a position on the scene, where people will pay money to see me and will come up to me afterwards and say that was a powerful, moving piece of work and I like what you do. And that's what I've always wanted to do. Since I was a kid I wanted to be a writer.

Exploring experiences with friends and peers

Talking about issues with friends and support networks

(F:164:3) talking your problems through to anybody who'll listen, your mates.

Support from friends in recovery movement who have encouraged participant to explore literature about dissociation

(F:104:1) This was after the breakdown, 'cos R*** (Participant C) was talking to me about dissociation and I bought a couple of books and I read them. (F:105:1) Yeah, and since then it's become a lot easier to deal with.

Longstanding, respectful relationships with social support networks

Experiencing respectful relationships with social support networks

(F:164:4) I mean I've got a very good relationship with Network for Change who are a local support group. You know, I regard them as friends rather than therapists. They come and I talk to them about my condition and that... (F:165:1) And they've been very patient with me, they've just supported me through everything, until I was ready to start talking about it. And that's what you need, people around you who will support you and treat you like a human being until you're ready to get to the point where you can talk about what's going on.

Longstanding/consistent relationship with social support keyworker

(F:164:7) I've got a longstanding relationship with them, like I've known D**** who's my key worker now since 1995. And he knows me. He actually knew I was bullied before I told him. He clocked it.

Taking part in film exploring his story was a validating experience

(F:166:1) I remember in that film you say, "What was it like?", and I remember saying, "Nobody's ever asked me that before." Nobody ever asked - nobody ever did. (F:167:1) it was good because you were encouraging me to go to therapy, R**** was encouraging me to go to therapy. And also it was a sort of validating experience, because it made me feel like being a mentalist was actually worth something. Like I was really surprised when I met you 'cos you fucking cared.

Developing techniques for dealing with persecutory voices

(F:135:1) God and the Devil still - God *and* the Devil? 'cos they're the same person - they still give me grief about it, but I just ignore it. Well I just kill them. I've got this thing. I kill the Devil. I think of an interesting way to kill him and I kill him and he shuts up and goes away. (F:136:1) I chop his head off, or I shoot him, or I strangle him or something and he stops hissing venomous hate at me.

F14) Medical model is not effective, and it perpetuates, rather than treats, social problems of western culture in which it is situated

Medication-dominated treatment is ineffective, unscientific, and economically motivated

Dominance of drug treatment is economically motivated

(F:127:1) they make a lot of money out of it. (F:128:1) There's Big Pharmacy selling these very dangerous drugs to us. And the psychiatrists are all in bed with them. I mean you go to a psychiatrist's office every pen has got Seroxat written on it, every mug has got Clozaril on it. They go on fucking lecture tours and get paid money to eat expensive dinners and get bribed by them. It's a fucking con! Big pharmacy is in bed with the psychiatrists and they fucking do this to us because they're mad.

Treatment that attempts to suppress voices with psychotropic medication alone doesn't work and is not based on scientific evidence

(F:126:1) It *doesn't* work! (F:113:1) They're more insane than we are. Because their ideology does not fit in with reality. There is absolutely no evidence that medication sorts people out. (F:159:2) I don't have a dopamine deficiency or too much serotonin, or some such *bullshit*. (F:168:1) it's like kids with ADHD, they're a problem to other people so they give them fucking amphetamines to shut them up.

Medical model focus on suppression of 'biological schizophrenic symptoms' felt like an abuse of human rights and mirrored participant's lack of self-worth

Being told by medical model psychiatrists that voices are a psychological flaw feels like last 15 years of life has been stolen

(F:162:1) (*Participant felt less confident about self when*) I thought I was biologically flawed, I *believed* what the psychiatrists told me. I thought it was all just white noise and noises in my head and gibberish and that's how I was experiencing it... (F:112:3) That's why I hate psychiatrists... They stole 15 years of my life and I'm not going to get it back. As far as I'm concerned it's an invasion of my human rights, I wanna sue the NHS.

Being told that he was biologically flawed mirrored and intensified sense of failure experienced throughout life

(F:167:5) I've always felt like a failure. You know it's what the medical model tells you. You're a biologically, genetically flawed fuck up, who has to stay on drugs and benefits for the rest of your life and please be quiet and sit in the corner and don't bother real people.

Medication is used to shut people up who are a problem

(F:167:8) That's what a mentalist is – somebody who becomes a problem to other people. And that's why they drug us and shove us on the ward because we're a problem to other people.

The cultural context of psychosis is ignored

Medical model diagnosis often pathologises normal experience

(F:127:6) The medical model is bullshit. It's not a biological flaw. Like 10% of people hear voices. Most kids have imaginary friends. They are pathologising a normal human experience with their fucking DSM and all the rest of this bullshit. You know they're giving *kids* these drugs nowadays. In like so-called primitive societies, you know Shamen hear voices and they're respected. If I'd grown up in a proper society I'd be a fucking prophet. God talks to me for fuck's sakes!

Moses, Jesus and Mohammed were all psychotic because they heard voices

(F:129:1) You look at any religious leader from Moses through to Krishna Murti. Jesus was psychotic. Look, at what Jesus did. You know he went into the temple, threw the money lenders out of it, went off into the desert for 40 days and 40 nights, went up a high mountain and heard the voice of the Devil and God and all the rest of it. Came back with a wild look in his eyes and said, "I am the way and I am the light." You know the man was deeply psychotic... All of them, all religious leaders are psychotic. Mohammed was psychotic.

In other cultures participant would be called a shaman, not a schizophrenic

(F:161:4) Even the most primitive societies have an innate respect for the insane. If I'd grown up in an African village, I'd be a witchdoctor, I'd be a Shaman. I'm a visionary. God talks to me for fuck's sake! I see visions. I have reached out and touched the face of God himself. I'm a fucking prophet - I'm not a schizophrenic.

Issues with medical model are situated within wider problems of western society

The values of Western society drives people mad

(F:170:2) I think this society drives people insane. Because we're all divided and the values of western society are completely fucked up and there's just not enough communal life left in the world. We're meant to be part of a tribe, we're social animals, we're supposed to have brothers and sisters and lovers and live together and that's been destroyed by western society, and everybody's going fucking mad.

Psychotropic medication seems to be Western society's solution for its social problems

(F:170:7) their solution to it is to drug people. It's crazy. It's like the prescription of antidepressants is going through the fucking roof, everybody's on fucking antidepressants. The solution is not to fucking drug people, the solution is to give them happy lives. You know you go to your GP and say I'm feeling shit. If you went

to a Shaman and said I'm feeling shit you know what he'd ask you? When did you stop singing? When did you stop dancing? When did you stop making love?
(F:170:14) The solution is not to give you a pill. That's just a chemical straightjacket.

F15) Addressing problems earlier on would have been more helpful

If breakdown could have been worked through and anxiety addressed, would have reduced severity of pain in later life

(F:99:1) If I'd met RD Laing (*laughs*) and he'd put me in his therapeutic community and maybe given me some Valium to take the edge off the anxiety, 'cos I was very, very scared, and helped me through it I could have gone through it and come out the other side. (F:165:7) if he'd asked me questions, you know a world of pain would have been avoided...

Suppression of sexual identity and its consequences could have been avoided

Felt that it wasn't socially acceptable to express true sexual identity

(F:130:1) It's difficult to come out...

Participant feels that most people knew about his sexual identity issues

(F:132:1) I don't know, when I came out most people said they knew anyway...

(F:132:4) she (*ex-girlfriend*) said, "I didn't realise it was a secret." (F:133:1) She knew... She was never worried about it. I think most people knew anyway. It was just *saying* it to myself.

Participant H – Individual Depiction

Now in her early forties and training to be a psychotherapist, (H) had two experiences of psychotherapy in quite distinct periods of her life. The first was when she was a teenager, following a psychotic breakdown that led to her being hospitalised, while the second was in her late thirties, and was part of her training. In between these experiences, she had several different careers and raised a family, and this life experience meant she entered psychotherapy the second time around with quite a different perspective.

After her initial breakdown, (H) seemed to find hospital a comforting place. She felt safe there and enjoyed the camaraderie. She also liked her schizophrenia diagnosis because it was good to feel that someone recognised just how much pain she felt. However, she began to feel an increasing sense of powerlessness from the strong medication she was given, and began to feel her diagnosis was an obstacle to recovery for a number of reasons. Firstly, it was felt to be an inappropriate description of her issues, and so treatment didn't address what she felt to be the real issues, which she felt were anxiety and depression. Antipsychotic medication had severe side effects, as did ECT, although she felt the latter may have helped, but was not sure because it affected her memory of that entire period. Finally, the diagnosis had become a terrifying through which she thought others viewed her identity and began to feel a deep sense of shame.

After a year of being an inpatient, (H) determined to leave the mental health system, and was supported by her parents to come off medication. However, this was against the advice of her psychiatrist, and she felt that to recovery she had to fight against the mental health system. After coming off medication, (H) describes feelings of coming alive again and her depression lifting. (H) began private family therapy with a psychoanalyst a year and a half after she left hospital. This opened up questions about (H)'s relationship with her parents and the difficult circumstances of her childhood. Her parents found the psychoanalyst was too blunt with them and ended the therapy after 6 months. However, (H) found that the questions that had been opened up initiated a process of self-questioning that she found to be central to her on-going recovery. She began to think about her experience of growing up in a pressurised home environment, which was dominated by her mother's need for (H) to be perfect and to excel academically. She had felt crushed by her mother's need for control and drove herself inwards as a way of protecting herself. By the time she was in her mid teens, she had split between a public self that excelled at school, and internal self that was immersed in fear and despair, and felt unable to enter into life as an adult. Making sense of these experiences seemed to help (H) to put her breakdown behind her and to find a life for herself. This making sense process also seemed to draw her into mental health, as a professional this time.

In the psychotherapy she began more recently, (H) found being able to speak openly and to explore her experiences helped her to understand both her mother, and their complex relationship more clearly. This has helped (H) to understand herself more comprehensively, and to heal her relationship with her mother. (H) felt in hindsight that if she had been offered psychotherapy at the time she first broke down, her recovery would have come sooner.

H1) Experienced a difficult childhood

Was a timid child and bullied at school for being English

(H:4:1) I'd always been a very timid child, when I was 4 we moved from S*** to S*****, I started school in S***** in not a great area. I was bullied mercilessly for being English. I can remember it really clearly how awful that was...

Life at home was difficult

(H:34:4) I think the way I can sum up best how my upbringing was, how my relationship with my parents was, is that when I read *Sanity, Madness and the Family*, the Laing and Esterson book, it just made sense.

Intense pressure from mother to be perfect and perform well academically

Pressure from mother to be perfect and perform felt like a Gestapo interrogation

(H:4:8) there was a huge amount of pressure, particularly from my mother to perform well academically and there was also a huge amount of pressure on both me and my brother to be perfect actually. There really was this *intense* pressure to, to behave in front of other people, and my mother's standards were high. (H:21:8) If I came first in a test it would be, "well that's as it should be." If I came second there was this inquest into what went wrong. And my dad used to joke about her being like the Gestapo, shining torches into my eyes, pinning me down, but it was very much like that.

Mother would scream at participant in front of other people, which wasn't a good environment for her to be in

(H:21:12) My cousin has said to me that all she remembers of our visits to their house was my mother screaming and shrieking at us. I think she was, she wasn't very happy herself, she was just so uptight. And unfortunately it wasn't a very good environment for us to be in.

Lived in fear of very strict mother, and feels that her illness stemmed partially from being squashed by her

(H:21:1) the intense pressure we were under. It just sounds so trivial but it wasn't. We just lived in fear of my mother. And I do remember - certainly when I was about 14 or 15 - hating her and wanting her to die because she was so... so strict. She squashed me completely, utterly squashed me.

Both parents had difficult childhoods

(H:4:5) my home life was 'interesting'. My parents were very loving in the way that they could only be loving, I mean they only knew how to be themselves. They'd both had pretty difficult childhoods. Not desperately awful, but you know quite... not easy.

Regular physical punishment led to feelings of being powerless

Parents couldn't cope with participant and her brother fighting, so was regularly thrashed and smacked

(H:23:10) we loved each other very much me and my brother, we're very, very close, but we also used to fight, and my parents couldn't cope with it. (H:23:14) But mum and dad were constantly, they were just in there, pulling us apart and thrashing us...

(H:23:17) my dad would sometimes get his belt off and he would do it in the ensuite bathroom... (H:23:9) We were smacked a lot, a huge amount.

Felt terrorised by the anticipation of being thrashed, and the feelings of powerlessness that came with it

(H:23:20) the horror of just being dragged across the landing, I mean that's where the terror of it started. And yeah the smacking was horrible and it really hurt but it was more about the threat of it and knowing what was coming and just being absolutely powerless.

Brother had also suffered period of being unwell related to childhood difficulties, but kept this secret from participant

Only found out recently that brother was struggling with auditory and visual hallucinations at the time of her own illness, and had later become addicted to heroin, which was perhaps his form of breaking down

(H:19:9) I found out a couple of years ago that at the same time he was actually experiencing quite severe visual and auditory hallucinations, far worse than I was having. (H:19:11) he hadn't had this complete breakdown, but he was struggling tremendously (H:20:4) I know these issues passed for my brother, but then he became a heroin addict, so that was his kind of, his way of breaking down.

Feels upbringing played a big part in what happened to herself and her brother, but not able to discuss this with mother because worried that it will hurt her

(H:20:1) we don't talk about this with my mother much - my parents. Because we just had this thing of, "Well what's the point, it'll really hurt her." Because we both feel that our upbringing played a huge, huge part in what happened to us.

H2) Traumatic and confusing transition into adolescence

Never felt normal

(H:8:5) I don't know how to put it, but I certainly never felt normal.

Tension at home when aged 14 wanted to become her own person

(H:5:1) at 14 I suppose I started wanting to be my own person, and I couldn't. It was impossible, and there's still that dynamic going on with my and my mother. She wouldn't know but it's quite interesting now for me to be able to see exactly how she behaves with me.

Participant felt she wasn't allowed to become an adult

Participant felt she was being kept a child by mother

(H:36:9) I had never had the opportunity to really become an adult. I think that's a lot of what was going on for me during the adolescence I was still being kept very much as a child. And I do now feel that I'm this barrier between my mother and my own children, 'cos she can't cope with them becoming adults. It's quite interesting to watch.

Mother's need for control prevented participant from growing up

(H:37:5) There is something about her that she needs to feel that she's in control.

(H:37:8) that's what she was very successfully able to do with me and my brother, to keep this very, very firm control over us, and I just didn't grow up.

Was scared to become an adult, and couldn't imagine living beyond 20

(H:37:10) I was scared of growing up. I actually do remember at about 11 or 12 being really, really scared of becoming an adult. And I'd always said that I would die when I was in my 20s, I couldn't imagine life beyond that.

Feelings of desperation were made better by cutting self with diver's knife

(H:6:1) these feelings of absolute desperation just started closing in on me and I started cutting myself and I still find that absolutely fascinating because there was nothing in the media at all about self harm and about cutting. (H:6:15) it did make me feel better... (H:7:1) (I used) a diving knife. And it had this huge serrated edge on one side and then a sharp blade and I used to use the serrated edge because that would tear chunks out of me.

Depression became suicidal feelings before 'A' levels

Felt alone one day and depression deepened very quickly

(H:8:8) I remember it was a snowy day, my brother had gone out to – the school was shut - my brother had gone out to play with friends, and I was waiting in for a phone call from my friends and nothing came so I sat and watched films and then my brother came home and said, "Oh everyone was wondering where you were." And I just remember that particular day I just went over the edge and I became really, really depressed. Very depressed very, very quickly.

After a half-hearted suicide attempt, could see school counsellor was out of depth and filled with panic

(H:9:1) I did try and cut my wrists, it was really half-hearted, and I did it at school and I went to see the school counsellor it was quite sweet 'cos even at the time I knew she was desperately out of her depth, I could see this panic behind her eyes (*Laughs*).

H3) Unresolved depression and anxiety led to breakdown

After the age of 14, nobody knew what was happening inside participant

(H:20:11) nobody knew what had been happening inside me really since I was about 14.

Broke down because she wasn't equipped to enter life

(H:37:13) I wasn't equipped to enter the world at all and I think that's one reason I broke down, because I couldn't face entering life. And so I had to do it in a very different way.

Pressure of a levels wasn't the cause of breakdown - completing her a levels was the legacy she wanted to leave her parents after her death

(H:3:6) it erupted immediately after my A levels... (H:20:8) I think a lot of the comments were "oh she always took things terribly seriously." It was this melt down because of my A levels, which to be honest with you I only did the A levels because I thought I ought to and a legacy to leave for my parents – "At least she did well at her A levels!"

Developed obsessions and paranoid ideas

Had obsessions about magpies

(H:9:7) I had this obsession with Magpies and unfortunately I lived in an area where there were a lot of magpies.

Not able to have thoughts at 13, 26, 39 and 52 minutes past the hour, but could relax when the time reached multiples of 7

(H:9:9) (When) it was 13 minutes past the hour or multiples of 13, so it was 26, 39, 52. See, I still know them. I was constantly watching the clock and when it got to those, I had to empty my mind and not think anything. (H:10:1) If I happened to inadvertently think about something during those minutes, it might go wrong. That's all I can think that there was this constant feeling of impending disaster and doom... (H:10:4) I did actually counterbalance it with 7, so 7 was ok, I could relax during 7, 14, 21, 28 etc.

Convinced that people could read her mind and used to fantasise about wearing a helmet to block people from getting into her head

(H:10:6) I used to think that people could read my mind. That was desperate actually, really, really difficult... (H:10:10) I did become more and more paranoid in that not, you know I was thinking that everybody was talking about me but also could read my mind, and I used to fantasise about having this helmet that I could wear that would block people from being able to get into my head.

Dreams were all about death and became more real than life

(H:11:1) I did keep a dream diary and I still have it somewhere... (H:11:3) death was everywhere in my dreams and they were bizarre and I got to a point where the dreams were more real than life. (H:12:1) The quality of what I was living through in my dreams was the same as being awake, there was not really much differentiation between how I was feeling awake and asleep.

Experienced obsessive feelings of self-loathing

Thought she was wasting air by breathing it

(H:12:12) I reached a point where I felt that the air I breathed was being wasted because somebody else could be breathing it. It really was like I was a waste of, you know, I was wasting air by breathing it.

Hated self so much, couldn't bear for parts of her body to be touching when sitting

(H:12:15) when I sat down I had to sit with my hands and my legs apart because I couldn't bear to touch any part of myself, I was... I just hated myself so much.

One part was still functioning, despite a feeling of disintegrating

(H:12:7) All this time I was actually still managing to do my schoolwork. (H:12:11) So a part of me was still functioning, even though another part of me was just rapidly disintegrating.

First contact with psychiatrist, was told that she was a very sick girl, but wasn't offered treatment

(H:13:10) (I) told the psychiatrist how I was feeling and he just said, "Well you're obviously a very sick girl" and I had another appointment made for 2 weeks' time and that was that. He didn't medicate me or anything, I don't think.

Attempted suicide with overdose to end chaos in head

Wanted to die because of chaos in head and desperate physical pain in chest

(H:15:13) I was just in pieces, I couldn't take the chaos in my head any more and I couldn't take the pain 'cos it was desperate, desperate physical pain as well, mainly in my chest.

Went on holiday, but knew she was going to kill herself when she returned with antidepressants she had been prescribed by GP, but had been saving up

(H:13:1) I'd had this holiday in Cornwall booked with some school friends of my best friend... (H:13:3) but I went there knowing that when I came back I was going to kill myself... (H:13:13) (I wasn't) taking the antidepressants my GP had prescribed - they were being saved up... (H:14:1) To kill myself.

Experienced moment of peace when took antidepressant overdose, but had forgotten to lock garage door and wonders now if she intended to be found

(H:15:1) I took the tablets, ran up and down the stairs a bit to get my blood running, going quickly, then I might have hid myself in the garage and fell asleep. And that was actually really lovely and I do still say, that that is one of the, the loveliest feelings I've ever had, that falling asleep, it was just absolute calm. And "thank God". Next thing I knew I was in A & E. Vomiting. I'd forgotten to lock the front door - again what's in the forgetting actually, I've wondered that for years. And so Dad knew that somebody was in...

H4) Treatment in hospital was a mixed experience

First contact with general hospital personnel after suicide attempt was mostly unpleasant

(H:16:1) Most of the nurses ignored me. One was really kind. But most of them, the attitude was, "Stupid cow's taken an overdose, we don't like people like that." And then there was the ward round on Monday morning. Consultant came round and he was *vile*. Absolutely vile to me until, he was saying, "Well I'll have to refer you to a psychiatrist", and I said, "Well I'm already seeing one." The relief. This guy, he must have thought, "Thank God I can get rid of this one now, nothing to do with me, you know she's already in the care of a psychiatrist."

Agreed to go to psychiatric hospital, rather than being sectioned, because it partially fulfilled a fantasy that there was something special about being mad

(H:16:9) psychiatric social worker came in, talked me into going to hospital, I agreed, 'cos you know partly I wanted it. It was all part of this fantasy of madness that I'd built up around myself because it was, although I was suffering immensely, there was also something quite special about being mad and being very different. So I agreed and again I'm very, very glad about that because I wasn't sectioned.

Treatment in hospital was limited to medication, OT and art therapy

Only form of treatment in psychiatric hospital was medication and Occupational Therapy

(H:27:1) it was medication and OT. So I knitted, the women could knit and the men made bird boxes (*laughs*).

Enjoyed art therapy and surprised that psychiatrist seemed interested in the results
(H:27:2) we did do art therapy and I did enjoy that. (H:27:6) those pictures were actually taken into ward rounds. The psychiatrists, my psychiatrist was really interested in seeing the pictures, which, looking back on it I'm quite impressed with because certainly my experience of working in mental health services in D**** (they're) not remotely interested in what the patients are doing in OT at all and there was no art therapy anyway.

Antipsychotic medication prescribed in hospital
(H:24:1) I'd been prescribed anti psychotics, I was having tablets every day and a Depot injection every fortnight. (H:25:1) Sulpiride and Depixol... (H:24:5) and then Kemadrin I think for the side effects.

Memory of year in hospital has been wiped out by high doses of antipsychotic medication and ect

(H:3:9) I'd been in hospital for about 6 weeks after my A levels, I then had a year of, it's mostly gone that year, I think it's a combination of having had ECT towards the end of my stay in hospital and having been on quite awful doses of anti psychotics, the year's wiped out.

Quite enjoyed the camaraderie in hospital, but feared becoming trapped in the system with growing feelings of loss of autonomy and powerlessness

Quite enjoyed hospital, staff and patients used to go out and drink together, but this was offset by a feeling that she had lost any autonomy she might have
(H:28:1) I kind of enjoyed myself in hospital because the patients and the staff would go to the pub in the evenings and we would be hammered every night. I mean it's appalling when I look back on it but it was quite good fun and there were a lot of young people in the hospital at the same time. But there was also this element of having lost any autonomy at all that I might have...

When she visited a locked ward, saw her future could be like One Flew Over the Cuckoo's Nest, and realised she could become trapped in the system

(H:29:1) I went onto a locked ward and saw what it was like on a locked ward in a long stay psychiatric hospital and it really was like One Flew Over the Cuckoo's Nest. And ...that wouldn't have been my future, but I could have become trapped within the system and just ending up going in and out of hospital in the same way that I saw people of my age doing it when I was working in mental health.

Liking the system meant she didn't fight it and become sectioned, which would have made her feel utterly powerless

(H:28:6) I'm very glad I wasn't sectioned because I would have been utterly, utterly powerless. I think my liking the label and liking being part of the system ultimately worked in my favour because I was compliant and so there was never any reason to section me.

After incident where a knife was planted on her, was discharged but then went back in for one week, which was horrific, and no longer wanted to be part of it

(H:29:19) I was discharged after 6 weeks. I did go back in briefly for a week's stay but it was horrific. By that point I just didn't want to be part of it at all.

H5) Diagnosis of schizophrenia seemed arbitrarily given, and was reassuring at first, but became frightening and needed to be buried in later life

Diagnosis of schizophrenia was given after describing some of her experiences to her psychiatrist, but it didn't feel appropriate

Was given schizophrenia diagnosis after suicide attempt, but psychotic depression diagnosis, which was also suggested, might have been more appropriate if she'd had a choice

(H:17:1) it was in the hospital within the first couple of days that I was given the diagnosis of schizophrenia. They were also bandying about psychotic depression, which if I would plump for any label, I was psychotic and I was depressed! But... But schizophrenia, I still don't know where that came from, yes, my thinking was incredibly disordered, I did have these - to use the terminology - paranoid delusions, but ...

Told psychiatrist about magpie obsession and fear that people could read her mind

(H:18:1) I think when I saw the psychiatrist, I might have mentioned something about magpies and birds. (H:18:4) I know I'd expressed that I was very concerned about people reading my mind...

Briefly heard voices after suicide attempt and on ward, and feels diagnosis of schizophrenia was largely based on this

(H:18:5) after I'd taken the overdose, I did hear these voices that weren't the people around me and I did kind of have these strange, you know, there were these voices and faces speaking at me. And I had a couple of other occasions in that first week of hospital where I'd heard something, heard voices. And I did say that that had happened to me, and I think very much on the basis of that this diagnosis was (given)...

Heard voices briefly in hospital room, but the main problem was agony and fear

(H:19:2) I was in a room where I think there were 3 other beds and there was nobody else in the room at the time, and I heard something that was kind of there, but I don't remember for the life of me what they were saying. But that was it as far as voices were concerned. The rest of it was just agony and fear, to be honest with you.

The schizophrenia diagnosis creates a powerful identity that was at first reassuring, but soon became very frightening

Loved the schizophrenia diagnosis at first because it gave her an identity as the mad person she saw herself becoming

(H:19:6) the diagnosis at the time, I have to say I loved it. I really – it gave me an identity, it gave me an identity as this mad person that I'd seen myself becoming. Because I'd been so utterly on my own with it...

In hindsight, her actions and behaviour being interpreted through the lens of schizophrenia was very frightening

(H:28:9) I was viewed in terms of my illness and my behaviour, my actions, were interpreted kind of through the lens of schizophrenia. And that's really, really frightening, looking back on it.

When a knife was planted on her by another patient, participant's protestations of innocence were seen as a symptom of her illness, and this became a turning point in realising that she had to get out

(H:29:12) there was one time, this guy who'd been in loads of times, he had this knife on him, he'd been holding it in the common room or whatever you like to call it, handed it to me when he saw a member of staff coming and said, "Look, look she's got a knife, she's got a knife!" And I wasn't believed when I said it was his and he denied that it was his. I then read my notes some time later and my denials of this knife being mine were seen as a symptom of my illness and it was at that point that things changed, because I just thought, "No I can't do this, I can't be part of this."

After receiving schizophrenia diagnosis, there was a sense of being written off

(H:64:1) I do feel that if people are seen as, are diagnosed as schizophrenic, they're kind of written off.

Realised how negatively the schizophrenia diagnosis was viewed when she disclosed it during a work interview

Schizophrenia diagnosis affected job prospects so stopped revealing it

(H:3:8) I stopped even revealing that I'd had this diagnosis when I started working.

(H:3:13) I started temping and at one of my temping placements they encouraged me to go to HR, to take my CV in and see what jobs they had. And – it went absolutely fine until I said that I'd had this diagnosis of schizophrenia, I'd been in hospital and I could see the shutters come down and that was it, the interview ended and I knew, I just knew that I was not going to get a job at that place, so that's it.

Felt judged on a label that felt had been arbitrarily given, so hid it for 20 years

(H:3:18) That's when I hid it, because I didn't want to be judged and I didn't want people to see me as this label that I feel I'd been quite arbitrarily given.

H6) Antipsychotic medication did not address mental agony or low mood, had severe side effects, and only started recovery after coming off it without psychiatrist's consent

Medication and ECT had severe side effects

The period of taking medication is a blur, and felt like she was hardly existing

(H:33:5) Everything is a real blur from that time when I was on the high doses of anti psychotics. I was hardly existing. I would get physical side effects, I would get tremors and I felt very, very thirsty, but it's so difficult to describe what it was like because I can't really remember.

Antipsychotic medication made words slip off the page, which was distressing because reading became impossible and wondered if she would ever read again

(H:32:1) I could read until the moment I went into hospital. (H:32:3) That was a really strange side effect of being on the medication, because as I came off the medication my ability to read came back. (H:33:1) I couldn't concentrate and the words slid around on the page. And actually for me that is a huge thing. I read constantly. And then all of a sudden I couldn't read and I think part of me was thinking, "Well I'm never actually going to be the same person again because am I ever going to be able to read a book again?" That was horrific.

After depot injection, used to be off the wall for 2 days

(H:33:8) My parents say that particularly two days after getting the Depot injection of Depixol, I would be absolutely off the wall for about 2 days, but I don't really remember.

Felt muddled and chaotic after ECT treatment, but not sure if that was the side effects of the medication

(H:53:1) I felt very muddled and chaotic after that (ECT treatment) anyway, 'cos of just ... I think that was the medication though. I wasn't me, I wasn't me at all, I was just this bundle of nerves really.

Once discharged from hospital, had to work against the mental health system to recover

Parents hated the effect medication had on participant and helped her gradually reduce oral medication without consent from psychiatrist

(H:35:1) They would not accept my diagnosis, they were less accepting of it than me initially. They hated the effect that the medication was having on me, and so without telling anybody we decided - 'cos I was fully involved in this - to reduce the medication I was on. We could do nothing about the Depixol, but the Sulpiride we reduced it very, very gradually indeed...

Parents persuaded GP to take over Depixol injection from psychiatrist, and it was gradually decreased

(H:46:6) Thank God, I mean, I've been very lucky in this, my parents persuaded my GP to take that over from my psychiatrist. And he agreed. He was quite reluctant initially but they just said to him "What would you do if it was your child?" And he said, "Ok I will, I will talk to the psychiatrist." And it was agreed that my GP would give, would administer the Depixol, and it was slowly decreased.

Started getting better when stopped taking medication

After slow reduction of all medication, depression and psychotic experiences begun to lift and participant started to come alive again

(H:35:8) by the following March - so it took a good 6, 7 months - I was off it entirely. And that's when something just switched on. (H:35:13) I suddenly started being alive again and certainly less depressed. The depression had shifted, the psychotic things that were happening to me in conjunction with the depression, were also lifting.

Getting better took several years, but begun when stopped medication, which participant felt had prevented her thinking for herself, and had invoked same feeling of powerlessness that had contributed to breakdown in the first place

(H:37:15) Getting better took a very, very long time. It took several years. (H:38:1) I... stopped taking the medication, that was the start. (H:38:2) the medication squashed me, controlled me, much as in the way I had been controlled before the breakdown, really. But once I was free of the shackles of the medication I was able to start thinking for myself, making decisions for myself...

Has had periods of depression in 25 years since breakdown but will not see gp for treatment because doesn't want to take medication

(H:42:10) I've certainly had periods of depression since, you know in the last 25 years I've had periods of 8 to 12 months of feeling absolutely wretched, but I won't go and see a GP about it, I won't take medication for it, I just live with it.

H7) Medication wasn't improving feelings of despair and hopelessness, so after 4 weeks was prescribed ECT, which corresponded with period where despair lessened

(H:50:1) The medication wasn't working. After four weeks. (H:51:1) I was still as bleak and as hopeless and despairing as I had been when I came into hospital so that wasn't good enough. And so my doctor - my psychiatrist - prescribed a course of six ECT. I think it might have been 3 a week over 2 weeks or 2 a week over 3 weeks. I can't remember. It's just gone. (H:52:1) What's very interesting is that my depression did lighten. And that's what was very interesting about that experience is that something did change in the weeks that I was having ECT. The despair did lessen.

H8) Parents were important source of support in initial stage of recovery

After hospitalisation parents fought for participant to get better

(H:34:7) afterwards my parents fought for me to really get better. And they laid everything in place.

Had gained a place at university but initially wasn't well enough and went to art school instead

Had a place at university, but wasn't well enough to take it and only found out years later that parents had not told her that the place had been kept open for a year

(H:31:1) I got my place at W**** to read English and American Literature, but I wasn't well enough. I didn't know, my parents didn't even tell me until a few years ago that my place had been held for me. I could have gone back the following year, or I could have started the following year rather. They probably didn't feel I was ready and I possibly wasn't, but I didn't get to make the choice.

With father's help, managed to gain a place at art school, but still felt emotionally wobbly

(H:36:4) I actually phoned the local art college, got myself an interview and got together a portfolio of my photos. And got a place. My dad helped me with the photography and doing the portfolio, but within 2 months I had this place at art college. I was still really wobbly, still very emotionally all over the place. Partly 'cos of what had happened to me, and also because I hadn't, hadn't really matured.

H9) Where therapy may have been unhelpful, but unsure

Had family therapy with a psychoanalyst for 6 months, but parents stopped going because therapist was too blunt with them, and not sure if it was helpful

(H:45:1) It had been suggested to my parents that psychoanalysis would help...

(H:45:3) It was an odd experience. It was... it was part of the recovery process. I

don't know quite how much it did help. My parents, I think we stopped going my parents found it too difficult 'cos she was quite blunt with them. (H:46:1) I would have time with her and then my parents would come in, so it was more family therapy than individual psychoanalysis. And they just found what was maybe being brought up, I think my parents found it too difficult which is why it stopped.

H10) Where therapy has been helpful

Has strong sense of how much therapy worked for her

(H:58:1) I know it works. I think I just have such a strong sense of how much it's worked for me.

6 months family therapy with psychoanalyst was challenging, and opened up questions about relationship with parents

Explored parent's relationship in psychoanalysis and how perhaps they hadn't been ready for children and this had been stressful

(H:23:2) one thing that I remember the psychoanalyst saying was about my parents.

(H:23:3) They absolutely adore each other, but they didn't cope very well with children. I think we were born a bit too soon because my mum got pregnant we were only about 6 months after they got married, they didn't have that much time together. And they were stressed, they had very little money and just, I know I cried a lot as a baby, so I think I was quite difficult, I think my mum just got very stressed very quickly, and although she loved us very much motherhood was possibly quite difficult for her.

Family therapy explored the effect of mother's crippling pressure on participant, and after therapy ended, this initiated a period of introspection and self-recovery

(H:49:1) I think what it did for me was start that process of highlighting things that had happened in my childhood that were not necessarily that helpful for me. And it was very much around how my parents had been with both me and my brother, with the kind of the very high standards, the *crippling* pressure put upon me in particular. I think it was in that therapy that a process in me was started because I know that I spent the next two years, I would have these long periods of introspection. I would think about myself a great deal, and it was like a self-recovery, but it was initiated I think by that experience of being in therapy.

Years later, begun working with a psychodynamic psychotherapist as part of psychotherapy training, and was finally able to speak about receiving schizophrenia diagnosis, which she had buried for years

6 weeks into the therapy felt safe enough to admit that she had received a schizophrenia diagnosis years before

(H:2:6) I buried it for so long... (H:56:4) I didn't tell her for 6 weeks what had happened to me, about the breakdown, about the diagnosis. Because I'd hidden it for so long, it wasn't something that was easy for me to say. I didn't want to cry in front of her. And I just had to get a sense of whether it was safe to do so. And I'm glad I did. She was, I mean she was a very safe person to tell.

Therapy has enabled participant to let go of the shame attached to the schizophrenia diagnosis

(H:61:1) the change in me since actually, I don't bang on about it, but it's out there. And that's been a very significant thing to have done I think, to have actually let go of the shame, because it was shame that was hiding it and so I'm not ashamed any more and again that's come through my therapy.

Therapy helped to explore the impact of relationship with mother, and helped heal the relationship

First 6 months in therapy, all she talked about was mother and how she wasn't allowed to have her own identity

(H:21:5) the first six months were about my mother. That's all I talked about. And just how she couldn't let me be myself. And ... it was that thing of not being allowed to be me plus having to perform extremely well at school.

Mother was terrified of participant being in therapy, but the process has actually helped to heal the relationship

(H:56:10) My mum was terrified of me being in therapy, absolutely terrified. But what it's actually done is it's helped me with my relationship with her. I never ever wanted to break it. It's just kind of healed things...

Therapy has helped participant to contain mother's inability to contain her own emotions

(H:59:4) my supervisor did say to me a couple of weeks ago, 'cos I was telling him what was going on with my mum and with A****, and he said is that why you're so containing? Because my mother is so uncontained and spewing everything out everywhere, now I think that's come through therapy. And through me being able to, to work through my... the things that I'd buried for so long.

Therapy helped to understand mother's own difficult childhood

Mother had an intensely rigid Catholic upbringing

(H:22:4) my mum and her siblings' upbringing was *intensely* Catholic. Very, very rigid Catholicism.

Mother's older sister deeply resented her being born

(H:22:6) I think my grandma had a miscarriage between my Auntie M*** and my mum. My auntie M*** deeply resented my mum being born so even when my mum was tiny she was really had a very difficult relationship with my auntie M*** which continues to this day.

Mother was a sensitive child and struggled in a strict, cruel convent

(H:22:13) she was an intensely sensitive girl and really struggled, really suffered through her upbringing and through being at this convent school. It was a Sisters of Mercy School and they were quite cruel.

Therapy has enabled participant to feel emotion, rather than fear it

Therapy has enabled participant to feel pain and then move on from it

(H:57:11) I think that's one very important thing that's come out of therapy, that I'm able to really feel pain and then it's ok. When a very close friend died 18 months ago,

I had something like 2 days of being prostrate with grief, I couldn't move. I just allowed myself to really be in it, to feel it, and then it passed and yes it still hurts.

Before therapy, used to feel that emotion would damage her and would need to bury it, but doesn't bury things now

(H:57:17) I think maybe I had this fear that strong emotion would damage me which is why I kept everything absolutely in and buried, whereas now I don't bury things.

Being able to talk openly in therapy has promoted change

Therapy has helped with talking about things in general, and in talking about it, things change

(H:59:8) I think another important thing about therapy is that I'm actually able to talk about it. And it's in the talking about it that things change.

In talking over and over again about childhood and loss of power issues, has healed relationship with mother, father, and other relationships

(H:57:11) I think it was actually just the talking about it. I don't know how it works (*laughs*). It was just going over it, over and over and over again. Saying it, hearing myself say it, all of that crap that happened to me as a child that I had no power over. It just had the result of changing the relationship in the present that I had with her, with my dad and also with other people, with my husband, it just has had the effect of me being very, very different in relationship with other people.

For therapy to be effective, you have to get through the initial desire to be fixed and believe in the process of the therapy

(H:58:2) if people can get through that initial thing of, "I want to be fixed and I want to be fixed right now!", and they actually go with the process, for me there's just something very much about just being with another person and I just, in my own work as a therapist, I think the people that... a lot of people say that the ones that really do stay are the ones that possibly get this sense of... my belief in the process. It's so difficult to articulate how it might work.

Since being in therapy for the last 4 years, periods of depression have been briefer and less of an issue

(H:41:13) And since being in therapy the depression, when did I... it's not been such an issue actually. Thinking about it now, having been in therapy for the last 4 years, I would say that I've only had one period of feeling very low in that 4 years and it didn't last that long.

Realised she had a terror of abandonment which helped prepare her for the abrupt end of her first training therapy

(H:57:7) What came out of it was I used to have this absolute terror of being abandoned by people, which is ironic given that my therapist abandoned me (*Participant's therapist became seriously ill and had to end the therapy*). I think that was actually a really important thing that happened, because what it taught me is that I didn't fall apart. I felt wretched, absolutely heartbroken, but it didn't kill me, it didn't break me down...

Being able to talk about these issues at the time of breakdown would have aided recovery more quickly and in a different way

(H:63:1) I assumed before I went into hospital, that therapy would be part of what I experienced in hospital. And so I was shocked that it just didn't feature. So I believe very, very strongly indeed that had I had that opportunity in hospital, things could have been different. I could have recovered in a different way and more quickly...

Strongly disagrees that therapy is not suitable for people with a schizophrenia diagnosis

(H:64:3) there is this attitude that was prevalent then, and is now, that, "What's the point? Medication will help them, but schizophrenia isn't a suitable thing for psychotherapy." And I disagree with that very strongly. I think that anybody, if they want therapy, if they want to engage in it, then something will be gained from it, whatever their diagnosis.

H11) Became involved in mental health as a professional

Worked at local factory supplying arms trade as a buyer and disliked what she was doing from an ethical perspective, so left

(H:41:5) Ethically I was very unhappy at working where I was working, because it was mainly military contracts and having the interests I had, I was very aware of certainly what some of the... actually there was one contract I was very unhappy about but that was coming to an end when I started working there. It was to do with selling things to Indonesia and I kind of, I did know what was going on in East Timor at the time. So it was horrible because I didn't want to work there but I also wanted maternity leave.

Began working in mental health, enjoyed developing relationships with service users, but felt time pressures made this difficult, and disliked practices such as physical restraint for medication non-compliance, so left

Developed an interest in the works of Freud and Jung at school and years after breakdown, took up suggestion of working as mental healthcare assistant

(H:54:1) I'd always been interested in it, I had discovered Freud and Jung at about 18... (H:54:5) and was absolutely fascinated by their writings. Then... many, many years later it was suggested to me, I was working as an agency healthcare assistant and somebody suggested that I would be good at working in mental health...

Enjoyed working on a forensic ward because had the time to develop relationships with patients

(H:54:10) I used to work on the forensic ward mainly as a healthcare assistant, as a mental health support worker, which I enjoyed because I was able to, it was really long stay... (H:54:13) built up a very good relationship with several of the patients on the ward.

Started mental health nursing training but no time to build relationships with patients and decided that it wasn't for her

(H:54:15) Started my mental health nurse training, wasn't for me. (H:54:20) there was no time to have any interaction with the patients whatsoever and I realised very quickly that this was not for me.

On psychiatric nurse's training, using physical restraint on patients who wouldn't comply with medication brought up feelings of powerlessness and decided she didn't want to continue training

(H:23:23) I still really struggle with that, and that's one reason I stopped working in mental health because I refused to restrain. It was different if the patient was attacking a member of staff or another patient. But that was quite rare, the more commonplace restraints were planned restraints when somebody wasn't complying with their medication. And I couldn't do it. I think the last time I did one I actually cried and I left shortly after that. Because there is something so awful about being that powerless.

Began a psychotherapy training

Current training as a psychotherapist is what participant had been looking for

(H:55:1) it was just right, it felt really right. Certainly academically it had been what I had been looking for...

H11) Other recovery factors

Seeing a nutritionist may have been part of feeling more alive again when coming of medication

(H:35:10) I'd been taken to this nutritionist, and I was taking vitamin supplements. I mean this guy is now quite, he's written books and stuff and he's very much into this idea of mental health and nutrition...

Finding confidence in self and having fun

(H:39:1) I also met somebody who became my future, and now ex, husband and because of – he could see how unhappy I was at college. So I just left and I started temping and it was just being out there, being among people, finding confidence in myself and actually also having a great deal of fun. (H:41:1) it was 4 years of hedonism really.

Participant C – exemplary portrait

Biography

(C) is married and in her mid thirties, and works full time as a project manager for the Hearing Voices Network. She regularly presents at mental health conferences, and has developed Hearing Voices groups for young people and prisoners. She was diagnosed with schizophrenia in her late teens, followed by multiple hospitalisations and treatment in a residential TC. She was also given a BPD diagnosis at around this time, which she felt came from challenging the forms of treatment given to her. Currently, she has a schizoaffective disorder diagnosis, which attempts to acknowledge the mood disorder aspects of her experience, and a dissociative identity disorder diagnosis, which acknowledges her dissociative experiences. She feels that this last diagnosis described her experiences the most effectively.

For (C), psychotherapy contributed to an overall recovery process that involved making sense of her life experiences, and how these had come to be expressed as psychotic symptoms. Viewed through this lens, (C)'s story seemed to exemplify the group experience in the following key stages.

TGi) Life experience and breakdown

(C)'s early life seemed defined by traumatic experiences. Her mother had been traumatised by an experience of being sexually abused as a child (although (C) didn't know this at the time), and (C) suffered a similar experience at roughly the same age. (C) grew up feeling vulnerable, wrong, lacking control, and terrified.

Experienced a first phase of trauma in childhood

(C:34:11) As a child, I guess I felt really vulnerable and really wrong, really bad and terrified and yeah, no control, and that's all I knew from quite a young age actually... (C:70:3) I was abused by a vicar when I was like 7, and part of a lot of people in my community were abused. The family-related stuff I find much harder 'cos I'm still... It's like I know that my mum was abused by people and that she was really traumatised. The idea that she might not have protected me from those people is quite frightening.

One way (C) managed this terror was to keep things to herself and internalise her bad feelings. Over time, these feelings turned into the notion that she had an alien living inside her. Later, another way these feelings were expressed was she would see a monster when looking in the mirror – a literal reflection of the way she felt about herself.

Early way of coping with trauma was to suppress it

(C:44:1) I think I really hid all the stuff in my childhood, so no one knew. I had like when I was 14, 15, sort of teenage, I believed that I had an alien inside me and that alien was gonna do bad, make me do bad things, or it was going to be bad in some way. I still wouldn't talk to people about it and I kept it all in.

This way of managing herself was effective to a degree, but was shattered by the experience of being raped in her late teens. All the previously squashed down feelings now began to emerge, and (C) had to drop out of university because she couldn't cope.

Experienced a second phase of trauma in adolescence

(C:70:2) I was raped as a teenager.... (C:46:1) after dropping out of university and- I told people about the rape I had in my teenage years, because that was, I was suffering with

depression, I felt crap, I was traumatised. And I was struggling to wash and look after myself and I was self-harming a lot, so I needed to drop out (*of university*), so I gave people that reason.

A downward spiral followed. While people could see how bad things were on the outside, nobody – counsellor, psychiatrists, family – seemed to have a sense of what was happening inside her, least of all (C) herself. The bad feelings intensified. Although she had first heard voices occasionally as a child, (C) now began to hear three voices often, who were all horrible to her. They would whisper conspiracies about aliens and intensified her paranoia.

Voices were triggered by memory of sexual abuse and rape

(C:44:7) I think I saw a poster saying that you could say no and obviously I hadn't been able to, and I'd had a lot of other traumas, not just the early childhood stuff, but throughout the whole childhood teenage (experiences), like layer upon layer. And that just triggered it. I started to get flashbacks. I started to get, hear 3 horrible voices, and get very paranoid again, (and to) believe the alien conspiracy theories, and it all just disintegrated.

While visions of monsters were less painful than actual abusers, psychosis was far from a fun refuge.

TGii) Inpatient and residential treatment

(C)'s increasingly bizarre behaviour seemed to confirm what others were thinking, that (C) must be schizophrenic. So it seemed natural to all, including (C), that she was taken into hospital and medicated. This seemed reassuring at first – at last someone knew what the problem was.

Participant's distress was seen as symptoms of a medical illness - this was initially a relief

(C:49:1) (The first time I told the psychiatrist) about being poisoned and followed and all this other stuff. And the voices and everything and they were really nice. They actually said, "It's ok, we know what's wrong with you, we see this a lot in people who go to university, you know, it's ok. Come into hospital, we'll just start you on some medication and get you back out there", kind of thing so it was like, "Oh" (*relieved*)... That felt like the nicest thing someone could say to me. It's like, "Wow, someone understands. It is me, I'm *ill*, but you know, someone can make me better."

However, because what she was experiencing was thought to be caused by a biological illness, medical treatment was focussed on medication, and this failed to address the underlying issues.

Medication reduced symptoms but didn't address underlying issues, which increased feelings of panic

(C:54:3) (Olanzapine) seemed to work really well, but then I was still paranoid underneath it 'cos I still believed in the conspiracy but I didn't know that I wasn't meant to *not* believe it. No one had told me really what recovery was, so they were like are you feeling better? "Well yeah, the voices are less and this is better, but I still believe in the aliens". And then was released and thought I was being followed, got really panicky, told someone at the day centre and then got re-admitted again.

Overall, medication also made (C) feel panicky, because the sensation of having her mind chemically altered felt panicky in itself. On top of this, the side effects of medication would also produce anxiety, such as when (C) began to lactate after taking Risperidone, because she believed it was further evidence of being taken over by aliens. More medication was then needed to combat the side effects.

Medical treatment impeded recovery

(C:118:1) I'd previously believed that the meds were keeping me 'well' 'cos I'd believed I was ill and I always thought I 'd need meds for life, and I'd been told I'd need meds for life.

(C:87:1) I think going into the medical sort of system and getting the diagnosis eventually through that, that sort of halted the therapy, so I'd have little bits of counselling, but then there was no counselling or therapy while I was an in patient or - even when I was sort of discharged, I was discharged to a CHMT...

As well as the treatment itself not addressing any of the underlying issues or feelings, the experience of being in hospital or in a residential TC was traumatic, because she was surrounded by other people's behaviour was frightening. This made things much worse (C:160:6).

(C) began to realise that one of the biggest obstacles to getting the treatment she felt she needed was the schizophrenia diagnosis itself, which was used in a way where her experiences were artificially split into different boxes.

Psychiatrist felt unable to work with participant's emotional content because it did not fit the diagnostic picture

(C:58:1) It's like, "I'm here to talk about your beliefs, your delusions, your voices. And it's ok you can feel distressed in relation to those, but if you start to feel like too emotional or too reactive or whatever, then that's like, that's not about the biological, that's something different."

With this approach, (C) felt that medication was often seen as the only treatment option.

Psychiatrist fixated on medication as only treatment for 'schizophrenia' diagnosis

(C:61:3) sometimes she'll (*psychiatrist*) sort of not plead with me, but very emotional, "Are you ready to go back on the meds now, (Participant C)?" (C:61:7) And I'm like, "I'll accept your help, I'm just not accepting the medication, 'cos I don't think that's helpful for me, but I'll do other things, you know if you give me a CPN or something to talk to, that would be fantastic". She's like, "No this is the treatment and you're not having a treatment for your illness." Really frustrating.

(C) began to realise that the diagnosis itself affected the way she saw herself.

Schizophrenia label reinforced pre-existing poor self-image

(C:42:1) no wonder I ran to that label and believed I was schizophrenic because it was like – "Yeah, I am wrong, there is something really bad underneath the surface that no one else can see". (C:42:4) And that did so much damage, it's taken me a long time - even before therapy - to kind of start to undo that.

In realising the power of the diagnosis to alter perception, and the power the was exercised by psychiatrists who used the diagnosis, (C) began to realise how much treatment felt like the experience of being abused as a child.

The power of the diagnosis mirrors the dynamics of past abuse

(C:38:4) I think schizophrenia's irrelevant. I actually think it's colluding with the abuse, I really passionately believe, really believe that if we talk about schizophrenia we're locating the problem with an individual and we're neglecting society, whether or not they've been through the traumas that I've been through. There's been stuff that's happened to everyone that gets that diagnosis and by saying it's them, it's biologically wrong. Even if you're trying to help them it's just reinforcing the abuse and the trauma that they've suffered their whole lives... (C:40:1) You're being abused because people think you want it, you're bad, you know, yeah. It's that you're the problem, not the abuse. It's, you've done something wrong,

and you feel that very keenly as a child and I grew up with this sense of me being the monster...

Increasingly, (C) realised that rather than helping her to recover, medical treatment either changed nothing, or made her feel worse.

Rigid diagnosis prevented appropriate treatment

(C:155:9) it's almost like the box itself of being schizophrenic stops people from thinking and the box of being borderline stops people from thinking and, even the box of being disassociative can stop people from thinking I think... (C:156:1) I just wish they'd get rid of the boxes, because diagnoses are meant to help you get the right treatment, but what they seem to have done for me, at least, is help me get the wrong treatment and prevented me from getting the support that I needed. Which is really damning I think. And it does make me feel angry...

However, when all of her experiences were taken into account, and she didn't feel split up into boxes, (C) felt diagnosis could be helpful in re-framing her experience in a way that helped her to understand it. For example, she felt the Dissociative Identity Disorder diagnosis made more sense to her than the Schizophrenia diagnosis (C:6:8-C:8:4).

TGiii) Psychotherapy that was unhelpful

Feeling unsafe was often a bad starting point. (C) feared her experiences might be too much for therapists, and that they would then want to get rid of her; whether this was her university counsellor (C:79:3), or a trainee psychoanalyst she worked with a few years later.

Trainee psychoanalytic therapist didn't know how to respond to participant having dissociative experience in the therapy session

(C:134:15) I think the few times I disassociated with her, she didn't know what to do with it and so she was sort of, I got the feeling that she was a bit unsure how to handle things and I kind of went, and I didn't feel safe, I lost my sort of - I lost trust in her I think...

Manual approaches, like CBT also felt unhelpful, because (C) was required to separate herself into boxes in much the same way she had experienced with psychiatric treatment.

CPN attempting to deliver therapy from a CBT manual was unhelpful

(C:87:4) I had a nurse who tried to do a bit of CBT for psychosis for me but out of a book!
(C:87:4) It just felt like why are you working through a book with me that's full of really cheesy ideas that don't relate to me at all... (C:89:3) she didn't appear to be very confident in what she was doing. So yeah, I guess I didn't have much trust that she knew what she was doing either...

Despite feeling this was not helping, (C) tried to play along because she wanted to please her therapist.

Desire to please CPN/CBT therapist by playing along with exercises didn't help (C:92:1) it's a common thing for me - certainly in my early days of therapy - is to try and please the therapist and the whole me feeling that I needed to actually produce an example and work through it the way they wanted to, didn't help.

Not being able to speak about what was going on was unhelpful, because often, what was being felt in the unspoken was an experience of power dynamics that reminded (C) of the dynamics of sexual abuse.

Unspoken power dynamics in therapy brought up memories of abuse

(C:13:5) I'm used to having psychiatrists that can section me and give me medication and not challenging and be very passive within that for fear – that's my childhood, and that's where it is now. So in therapy I would do things like I wouldn't ask to use the toilet, 'cos it's a horrible boundary cross for me to use the bathroom in the therapist's house...

TGiv) Psychotherapy that was helpful

Some tools were useful, for example, guidance on 'the traps of thinking' (C:95:2). However, more than anything, being able to freely explore the meaning of her experiences, without the rigidity of diagnosis getting in the way, was helpful.

Not having to engage with the framework of diagnosis was helpful

(C:57:1) The good thing about therapists is they're not about to diagnose you. Especially a therapist you pay for. "She's working for me!" This is how I remind myself. Yeah, that's it. Emotions were something I feared within psychiatry and they were discouraged.

The quality of the relationship was important, because this helped (C) to develop a sense of trust, which was needed before she could think about going more deeply into the most feared voices and the experiences that she felt they represented.

Developing a sense of trust in therapist encouraged participant to explore traumatic material

(C:80:10) before I build a relationship with a therapist, it takes me a long time to really feel there's some trust there, so I take spend a long time sussing it out... (C:78:1) I'd been so used to keeping secrets for my whole life, that the idea of talking to someone about it just seemed really alien. (C:92:7) It's taken me a long time to even mention unhappy things to therapists, I've been a very compliant – probably a pleasure to treat. (C:43:3) (Because the fear is that) once they see past the nice person, they'll just see all this yuk that came from your childhood that will be really bad for them, they won't be able to cope with it. (C:16:12) the more that I and my voices see that she doesn't do anything terrible to us, no matter what we kind of bring, the more I'll be able to trust her. And once I can trust her we can go a bit deeper into some of the stuff.

Once this had been established, a more open and reflective, less directive, approach to the therapy helped (C) make her own associations.

Experienced psychoanalytic psychotherapist helped participant make her own associations
(C:107:13) I described the person who abused me as kind of like cold and sort of a bit alien, and he just made the link between that and my alien... (C:107:20) Whereas (*where other therapists may have been more directive about a link*) he did it in a way that was just wondering if there was a link, rather than "I wonder if the alien is your abuser?" It just felt helpful.

Therapy helped participant explore feelings underlying symptoms

(C:41:6) certainly from therapy, what's come up loads is the idea that I just feel that inside I'm just a squishy black mess of badness and that if anyone really sees what's inside me, that's it. They'll get bad, or someone will hurt them or they'll just reject me or hurt me and I deserve it.

Making these associations has been painful, but necessary, because this process has helped (C) to understand herself better. In so doing, she realised that some of the things she experienced had a rationale that was far from mad.

Confronting trauma in therapy has been painful, but has helped participant understand psychosis as a form of disowning traumatic experiences

(C:28:1) Therapy's confusing. Therapy for me is like having your insides ripped out and it hurts so much, it hurts more than I've ever, ever thought anything could hurt, looking at your stuff as having meaning hurts it's a lot easier to talk about it in terms of alien conspiracies and

kind of - one time I went saying I'd kind of started to believe that I was, Bladerunner, yeah, after something I'd been in therapy for maybe a few months, I kind of went, I'd started to believe that I was one of these, I can't remember the word, but yeah these Nexus 7, whatever it is. Which basically meant that I didn't have a history and that I was basically made and all of this stuff that I was remembering, all the bits my voices were remembering weren't real and I was just given those memories and that I'm not human...

Through this exploration, (C) has come to understand psychosis as a form of symbolic protection from the deeper, more distressing actual experience.

It was less painful for participant to think of abusers as literal monsters

(C:34:15) (As a child) What I was escaping from was the people who were hurting me, and so instead of having people who were hurting me as being people, they became monsters or aliens or *things*, separate. (C:29:3) Talking about it now I can see it makes so much sense 'cos I didn't want it to be real, and I have a very metaphorical kind of brain, so some people might be, "*As if* this is happening", for me "*This is* happening", and it gave me a lot of comfort actually.

(C) found that in being able to address the meaning of her painful experiences there was no longer a need for the protection of psychosis (C:31:2-C:38:3). Moreover, rather than attempting to suppress these kinds of experiences in treatment, (C) realised that bringing these experiences back into her conscious mind was the key to on-going recovery.

Being able to explore experience, rather than receiving directive interventions has helped participant to bring trauma back into self rather than dissociating

(C:154:1) I think sometimes just exploring it from different angles in an arty form helps me work out what I feel about it and integrate it 'cos I don't want it to be split forever. I figure these are my memories and these are my experiences, and I just wanna get to the point where I feel safe enough to bring them back into me, rather than have them as separate...Weird.

Part of this on-going recovery process has involved getting closer to the voices and personalities associated with them, so that they feel like they belong to her.

Naming the voices helped give them an identity

(C:40:5) Naming the voices has been really helpful to me... (C:40:7) 'cos names are powerful, and you and the voice can choose a name together. And Alfie I chose for her because she was very much Monster Girl, 'cos she thought Monster Girl was actually with the monsters. And she believed that she was a monster and because of the things that had happened to her. She is basically me as a child. I really thought I was a monster when I was little. I saw monsters and I believed I was one. And she still carries that as a voice or as an aspect of me...

Psychotherapy that facilitated this meaning making and the recovery of all aspects of herself, has been the key to her on-going recovery.

Without therapy, participant felt they wouldn't be alive any longer

(C:71:9) without therapy I really wouldn't have the opportunity to do that (*work through trauma and make it less painful*), so I'd be forever completely subjugated by these experiences. I wouldn't be working and I wouldn't be having a relationship like I do. And I wouldn't, yeah, I wouldn't be here really. I think I might, might not have survived if I hadn't have had the opportunity.

TGv) Recovery

Overall, (C) felt the first step of recovery was to appreciate that her symptoms had a meaning that needed to be addressed. This idea initially came from a community support group, and this drew her toward HVN.

Encountering professional and peer support bodies that encouraged participant to understand meaning of psychosis was helpful

(C:71:15) Network for Change, they were - and the Hearing Voices Group - they were like huge 'cos they were the first people that really said, "There's a meaning here, there's something, this isn't just an illness randomly grabbing you and dragging you like a demon into hospital where other people make you better. There's something here".

This was challenging, because,

Peer support networks encouraged independence, but participant found it easier to see herself as ill initially

(C:72:3) The first time that someone mentioned that the voice might be representative of an abuser - my abuser - I was really angry at them. So I wasn't ready for it. Still not entirely ready for it... (C:157:13) I was really resistant to this (*peer support*) for the first couple of years, this was when everyone else was doing it, running around me going, "Look there's another way!" And I was like, "No I'm ill!"

However, in hindsight, (C) realises that,

Without taking charge of own treatment journey participant felt she would have ended up in long-term residential care

(C:157:2) Even telling part of this story, you kind of realise that things were so stuck and people were starting to see me as a long-term severely, never-gonna-get-better - (C:157:6) it's not just my word, it's kind of what's written (*in participant's psychiatric notes*), and there's this one, a sort of discharge CPA thing that was saying I need long-term sort of residential care and they were gonna look for that.

In order to recover, (C) had to first work against a system of treatment that she felt stuck in, which often worked against the things that were required for recovery.

The mental health system is a dumping ground and is not helpful

(C:157:19) it's like it's so stuck the whole system, it's very hard to see alternatives when you're in the middle of it... (C:158:1) it's nothing about health... It's social control really. Yeah. Dumping ground. I think it's really sad for those really good people that work in it because it's not that it's full of evil people that try and hurt them and I think if they heard the story that I've just told you, they would probably feel really bad because they're trying so hard to make things better, but they're operating in the wrong system...

On important step was to reduce medication that had severe side effects and reduced her capacity to be in relationships, and for work.

Participant needed to come off medication to function more fully at work

(C:118:4) I knew that there was no way on all the medication I was on that I could function in the mornings getting to work. (C:119:3) J***, who I was going out with at the time would wake me up, bring me coffee, I'd fall asleep holding the coffee in bed I'd kind of fall asleep, and then he'd take the coffee away and then he'd try and get me breakfast, so bring me some Weetabix or something and then wake me up again and I'd try and eat Weetabix and then have to go back to sleep and then he'd wake me up again and *again*, and eventually I'd be able to get out of bed and it was just - yeah, really hard... (C:122:7) over the course of maybe a year, I'd reduced the dose quite dramatically so I was taking a lot less than I had previously and coping. I was having sort of increased experiences, but I was coping with them.

At this time, (C) also realised that psychotherapy was also going to be an important way of facilitating her recovery, and that to make full use of it, she needed to access the emotions that medication had blunted.

Participant needed to come off medication to function more fully emotionally

(C:123:5) (Medication) was putting a block between me and the world... (C:125:1) I remember sitting on the sofa with J*** - all within a very short space of time - and just feeling so disconnected from him and just like there was a big gulf between us and it wasn't as if we'd had an argument or anything, I just didn't feel fully present and so all of those things together I just thought I need to get off them now.

Initially, coming off medication made (C) feel worse.

Shortly after coming off medication became paranoid and experienced increase in psychotic symptoms

(C:126:7) I started to believe that my thoughts were leaking out of my head and there were people doing brain surgery on me and I was still trying to work at this time as well, so trying to get on the tube with people like having all my thoughts felt very violating. And yeah, I had to stop working 'cos I just couldn't go out and I also find it very hard just to make decisions, I found it hard to stay present, J*** felt as if he'd lost me, as if I wasn't there... (C:128:1) Time didn't really make any sense in that, in that period, but I think it was probably, I was only off work for maybe 2, 3 weeks. I think those kind of experiences lasted longer, maybe a couple of months, but they were most intense for that sort of 2, 3 week period.

During this time she met with much resistance from her psychiatrist, who believed that medication was the one thing that had helped (C) to become more stable, and that in coming off it, she was becoming unstable again. However, (C) found that her psychiatrist's anxiety was a powerful force in the mix, and it was this that seemed to put her stability at risk more than anything else.

Psychiatrist's anxiety provoked paranoia in participant

(C:66:1) I spent a lot of energy dealing with psychiatry and less energy dealing with myself I think sometimes... (C:67:1) They were really, *really* anxious it was like we were trying to calm them down. But that made me bad 'cos then the voices were yelling at me and I was having this thing where she was telling me I was more likely to kill people and kill myself and that this illness wouldn't go away, just 'cos I wasn't taking medication... (C:68:1) (laughs) They were yelling that it was right, that I was ill, that I was crazy, stupid... (C:68:8) I just got stressed and I think the (more) stressed I get, the more stressed my internal world gets. And without J***'s support I would have gone back on the meds, it just felt too much at that point.

Paranoia provoked by psychiatrist's anxiety deepened, however, this was used as evidence for why participant needed to be on medication in the first place

(C:69:3) I could feel people in my head, experimenting on me and all that stuff and of course, in retrospect, *that was psychiatry*, that was the doctors. They were, they were trying to do stuff and I felt very powerless and then that set off my beliefs again, which then reinforced their idea that I needed the medication... (C:127:1) I tried to get help from the system again, but they were like, "Take the meds or don't, you're not going to get anything else from us, so it's like if you don't take the meds we're not going to help you, there's no other option, there's no therapy or anything". (C:69:9) But he (*husband*) held onto the fact that this was understandable and helped me get through it. This was before therapy.

Having come a long way in her recovery journey, (C) now feels that her voices and internal personalities often express an emotional reaction to an external event that had not consciously registered (C:153:1-12). This allows her to address the external event and to calm the voice itself, because she understands *why* the voice is anxious (C:149:4-C:149:10). In understand more about herself, (C) now feels that it would be impossible to return to an earlier time where it was possible to believe she was schizophrenic.

Having understood psychosis as a way of escaping from trauma, it's not possible to go back into a full psychosis

(C:31:2) It's kind of like the Matrix. Once you take the pill, you can't un-see that. You can't un-see this different world and, as much as I'd like to - and sometimes I would like to go crazy again because it'd be easier, it really would be easier sometimes - you can't un-see the sense that you've found in it. I can kind of have a break from the sense and maybe give myself a bit of respite with psychosis, but I can't ever go back... (C:38:1) I don't think I'll ever go crazy again. Not properly. I think I might go through periods of psychosis to get away from all this, but I don't think I could ever spend eight months in hospital and believe I was schizophrenic.

Participant G – exemplary portrait

Biography

(G) is in her early thirties, and is active in mental health politics. She is a leading figure in the Hearing Voices Network, and presents regularly at mental health conferences. She is currently completing a Phd in psychology. (G) experienced a breakdown in her second year in university, in which she heard a single voice commenting on her actions. Although she initially found this voice helpful, following medical advice, she was hospitalised and diagnosed with schizophrenia. This was changed to Paranoid Schizophrenia when she was twenty. The medical treatment that followed led to, what (G) described as, an internal civil war, in which the initial voice multiplied into twelve. She feels during this time, she entered hospital an unhappy teenager, and left a schizophrenic (G:42:4).

For (G), the process of recovery began when a psychiatrist suggested that her experiences might be meaningful. This revelation propelled her into HVN, in which she became active. She completed a BSc in psychology, and then an MSc, and began lecturing internationally on mental health. In experiencing a sense of professional achievement, her self-esteem increased and her voices became less frequent and persecuting. However, despite her success, she felt there was still a deep underlying unhappiness, and in order to further her recovery, she would need to explore her experiences more deeply in psychotherapy. She has worked with a psychoanalytic psychotherapist for a number of years now, and feels that this on-going exploration of meaning has helped to transform her symptoms to the point where she hears voices infrequently. When she does hear voices now, they tend to be helpful, and help her to think about what is going on around her.

In making sense of her life experiences, (G) had gained a deep understanding of both herself, and her story. This story seemed to exemplify the group experience in the following key stages.

TGi) Life experience and breakdown

(G)'s childhood was complex and traumatic. Although her relationship with her mother is now loving and supportive, (G) felt as a child her mother was not able to be tactile with her (G:10:7-12). This seemed especially difficult, because her father physically and mentally abusive, perhaps due his own difficult childhood.

Difficult family relationships as parallel aspect of early trauma

(G:10:1) I think again it was only many years later that I was able to understand that I was physically and emotionally abused by my dad... (G:8:2) My father was sort of neglected and abused as a child himself, and I think in some ways was a loving parent but not a good parent. And I think it's very hard to be a good parent if you've never had that yourself. And though I don't believe illness runs in families, I do believe distress and trauma runs in families.

(G) was sexually abused by paedophiles at nursery school and she feels that her difficult family environment meant that she was less equipped to cope with this trauma.

Sexual abuse was one aspect of early trauma

(G:7:1) part of my sort of painful childhood experiences, the first of which I only want to refer to quite briefly 'cos it's something I still find very, very difficult to talk about, but was... being

enrolled in a nursery school that was run by a group of organised and sadistic paedophiles and very, very extreme sadistic abuse at an early age.

(G)'s way of coping with the agonising feelings that followed these experiences was to bury them.

Early trauma had been buried

(G:6:1) I think I was somebody who literally buried my past, but I buried it alive. And so throughout all of my adolescence and early adulthood, and to some extent even now, it was almost like screaming to get out.

As she grew up, she felt that she developed an internal split to deal with these experiences.

Developing an internal split as a way to survive trauma

(G:6:3) And throughout adolescence there is almost like two E*****s (*Participant G*), there was the E***** who worked very hard, did very well at school, got this you know slew of impressive exam results, was well behaved, was well liked, was very good at placating people, at keeping people happy. And then there was another E***** which was hidden, which even I wasn't really that aware of, who was absolutely crippled, and filled with fear and shame and horror, and misery. And hopelessness. Which was also this sort of crucible really of incredibly strong emotions, so emotional – hate, anger, resentment, fear - and those kind of emotions, which were very, very frightening.

Self-harm was one way of both managing this split, and also a way of expressing the pain and despair she felt.

Self-harm was a way of both expressing and managing internal chaos pre adolescence

(G:11:1) I remember when I was about 12, beginning to harm myself, I used to burn my arms with an aerosol. I used to get these spectacular blisters and it looked hideous... (G:73:1) My self-injury formed – again it was almost like a communication, in way like expressing the inexpressible and putting the pain on the outside. It was like battle scars, like proof of your suffering in a way and I think also my body was a focus for all the pain and despair and anger and rage... (G:74:1) I think at worst it cost me some awful scars and some awful hospital admissions, but at best it saved my life, so you know, I owe it more than it cost me in a way.

(G) also developed rituals to try and manage her feelings of terror.

Initial symptoms appeared as internal chaos deepened

(G:19:1) it started off with, I guess you'd almost call them like OCD experiences. It was this pervasive sense of guilt. So for example, if I'd seen like a piece of rubbish on the street and I hadn't picked it up then I was tormented by the idea that someone would slip on it and it would be my fault.

Like several other participants, (G) first heard a voice as a child. However, it was heard internally, and seemed to have the function of commenting on her thoughts.

The first experience of voices was in childhood, but participant only noticed them in hindsight

(G:24:12) I'd had them as early as the age of 5 and being at school and struggling with a maths problem and hearing a voice say, "She is struggling with a sum." But it was internal... (G:25:1) It was just like this human utterance, but without gender, or age. And when I was that young, I think I just didn't really think anything of it, I just assumed that was something everybody had.

Also like many participants, (G) experienced a second phase of trauma in her late teens, which involved being bullied by a fellow student at university. This traumatic experience seemed to do two things. The first was, it seemed to smash through the structures of self management she had constructed, and delved deep into the pain that was held there. The second was, it seemed to reinforce earlier internalised messages.

The second trauma replayed an ingrained internal message

(G:66:1) ...I think, you know, I subconsciously had probably learned this message - or had been conditioned into this message over many, many years - is that you know, "People will harm you and there is nothing, you are powerless to prevent it. There's nothing you can do about it."

She began to hear a voice regularly at this point, which was similar to the commenting voice she had heard as a child.

The first experience of external voice was in response to second phase of trauma

(G:26:7) I think it appeared after this increasing period of this sense of unease and anxiety and dread, of about a few weeks I think. And then that culminated in this voice suddenly appearing, like literally overnight, externally, sort of commenting on what I was doing...

(G:24:8) it began in a very, very banal neutral way, in terms that all it used to do was narrate what I was doing in the 3rd person. So it would be like, "She is going to a lecture, she is going to a bar, she is going to the library."

The second phase of trauma experienced by (G) changed the character of the voice.

Secondary trauma changed the character of the voices

(G:29:6) leaving the seminar in those circumstances (*after being picked on by fellow student*) I would notice the voice would say, "As usual she is leaving the room." But it would sound angry. And this was quite an extraordinary revelation, 'cos I'd never heard the voice sound angry before....

However, (G) found what the voice expressed was useful, because it was a deep sense of anger that she found to openly express herself.

The voice expressed emotions that had been suppressed

(G:30:1) (*the voice*) seemed like this really kind of creative and insightful discovery that actually this voice was representing my own unexpressed emotion. And you know my own sort of sense of disowned anger, but also my own disowned sense of entitlement, you know, "I matter, you know I have a voice, I have a right to say what I think and be heard."

However, after telling a friend about the voice, (G) reluctantly agreed to see a doctor. Somewhere in the back of her mind, she felt that having her pain recognised by someone would get her the help she secretly craved (G:31:12-15). However, her doctor's reaction to her description of the voice unleashed a whole new wave of anxiety and despair.

Voices were seen as sign of extreme mental illness both by doctors and society

(G:51:1) it was sort of this abstract, arbitrary symptom of mental illness, you know a piece of biological bad luck to be endured, rather than a complex, or significant, or meaningful experience to be explored... (G:32:15) (*The psychiatrist*) told me at one point, E****, you would be better off with cancer, because cancer was easier to cure than schizophrenia. And even if you believe that, to tell that to a 19 year-old woman is just so cruel and demoralising.... (G:33:1) And I think that was the worst, that sense of powerlessness, you know, that there's nothing you can do to help yourself except take this regime of medication and hope for the best. And that was pretty much the message that I was getting.

(G) felt this negative interpretation reflected society's reaction to hearing voices. Looking back, (G) felt she soon assimilated this negative way of looking at herself taught her to mistrust herself.

Perception of voices as extreme mental illness taught participant to mistrust herself

(G:37:7) it was like the friend had passed the baton to the GP, who passed it to the nurse who passed it to the psychiatrist who - worst of all - passed it on to me, that hearing voices is this bizarre, rare, extraordinary sign of extreme mental illness and you know chaotic, disturbed emotions and behaviour, and you know, you're fucked basically... (G:39:2) I was frightened about the idea of being mentally ill and what that would mean for me. I was finding it harder and harder to relate to the people around me, my work was suffering. And just this real vicious cycle and again, what you picked up on was just hopelessness - nothing else driving everything.

This mistrust deepened her distress, and necessitated medical treatment, from which point (G) declined rapidly.

Psychiatric treatment of the 'symptom' then necessitated further treatment in hospital

(G:39:6) when I saw the doctor again, I think she was concerned about me and she said, "We're not sure what's going on with you and I think it would be really good if you came to hospital for a few days just so we can get a better idea of how to help you."

TGii) Inpatient and residential treatment

Rather than feeling a place of safety, hospital felt like being traumatised all over again.

Being surrounded by other traumatised people was in itself traumatic

(G:41:2) I came onto the ward and it was awful, you know it was double locked doors, bars on the window... (G:41:4) There was people who were really institutionalised, there was people who were you know sort of very disturbed and distressed and violent... (G:41:8) And I knew immediately that if I was still going to try and recover this lost sense of self, 'cos that was still how I was thinking of my difficulties, then I knew this hospital wasn't going to be the place to do it. And I said sort of a few hours after arriving, "I want to go home, I don't want to stay here." And I was told, "If you leave, we'll section you."

Worse, there was no relief from the pain, because the only form of treatment was medication, and this had no effect on the voice that she had been told was sign of the disease that had consumed her.

Antipsychotic medication was the only form of treatment on offer, but seemed to make things worse

(G:42:7) I was put on a very high dose of medication, of Risperidone, which didn't really help, if not actively made things a lot worse... (G:44:1) ...it had no affect on the voice at all, but it was hugely sedating. So I'd be sleeping all day, piled on a huge amount of weight...

Not only did this attempt to suppress what she was experiencing not address the underlying issues or the pain associated with them, it actually made the situation markedly worse.

The psychiatric attempt to suppress the voice created a psychic civil war inside participant's mind

(G:44:5) ... I was being told it (*the voice*) was a symptom of schizophrenia (and) that I should ignore it, that I should distract myself if I had heard it, and which I started to do. And it was this process that I always refer to as a sort of psychic civil war, because you were being encouraged to take an aggressive stance against your own mind... (G:46:1) that sort of fracture that was in me, this sort of splintered self almost, was just becoming, was rupturing

by the day almost. And what would ultimately happen is that the voices multiplied and became stronger and more aggressive, so what began as one quite neutral voice ended up as 12 voices and one voice, this dominant voice, emerged which... that was... horrendous.

The medical attempt to suppress voices involved hoping that something would go away, rather than listening to the problem

(G:44:10) if 12 people came into this room now, and if some of them were very angry, some of them very distressed, some of them were just filled with despair, and some of them might seem quite frightening because they are so angry. And we sort of have two choices over what we do with them, we either sit down with them, try and comfort them, listen to them, make an attempt to understand why they're so angry or so distressed. Or we can sort of lock them in a room and bolt the door and hope they calm down after a while.

(G) thought hospital unwitting takes up the place of an abusive parent, fostering dependency and helplessness at the same time as teaching the individual to mistrust their own experiences and learn to fear them as symptoms of illness (G:40:1-7). Combined, these hospital experiences led to (G)'s emotions deteriorating so rapidly that they couldn't have let her go (G:42:1-2).

The fantasy of hospital as sanctuary was replaced by feeling of being destroyed

(G39:9) I think I liked the idea of you know just being taken away from it all and having this sort of place of sanctuary and respite and it's like this cruel, cruellest irony of all is that the place that is set up to offer you that, which is the psychiatric system, to so many people is the place that nearly destroys you, once and for all.

Looking back on her journey, these forces combined led to the belief that

(G:42:4) I think I went in (to hospital) a sort of distressed, unhappy teenager, and I came out a schizophrenic.

Realising that her state would only continue to deteriorate, (G) resolved that she would have to leave hospital in order to get better. This required,

Faking compliance with medical view of schizophrenia was the only way that it would be possible to leave hospital

(G:52:4) I was finally discharged after the first admission, after learning you know, from other patients on the ward really, that if you want to get out you have to lie your way out of there. And I just told them what they wanted to hear.

After leaving hospital, the experience of trying to reintegrate into society with a stigmatising diagnosis like Paranoid Schizophrenia turned into a fourth phase of trauma.

After hospital, social stigmatisation became a further traumatic experience

(G:63:8) (*back at university, peers knew why she had been hospitalised*) I'd enter a room and would hear a flurry of laughter at the other side. I was sort of goaded into putting a cigarette out on myself in front of this group of students who then all cheered when I did so. And I remember being grabbed by these two students who sort of brandished my arm with all of these injuries and would say, "Look, look what she's done to herself!"

(G) dropped out of university and lived with her mother.

Social isolation compounded issues

(G:68:1) a typical day for me during those times would be, I would get up very late, usually 2 o'clock in the afternoon and I would get dressed and made up, so almost like having nothing better to do. That was almost like a way of filling time.

Her sense of terror and despair now compounded by the belief she was suffering from a brain disease and the traumatic experience of hospital, (G) found more extreme ways of managing her emotions.

Self-harm directed by voices

(G:70:4) the injuries were very, very severe. And the voice would say, “You're right handed, so you don't wanna lose your right arm, so you should cut off your left arm, because then you can't use your left arm to damage your right arm” (laughs).

Trepanning as a way of attempting to rid self of voices

(G:61:4) I was so sort of tormented and demoralised by that voice that I wanted to drill a hole in my head to get him out. And it wasn't a suicide attempt... (G:61:11) But that was how desperate I was to get rid of him.

TGiii) Psychotherapy that was unhelpful

(G) did not speak about any aspects of psychotherapy that she found unhelpful. While other members of the group may have exemplified this thematic grouping more effectively, it is (G)'s overall experience, in particular, how exploring the meaningfulness of psychotic symptoms led to their transformation, that exemplifies the group.

TGiv) Psychotherapy that was helpful

After a psychiatrist encouraged (G) to think of her experiences as meaningful, she became increasingly involved in HVN and exploring her own experiences. This was the start of rapid recovery that turned her into a poster-girl for the recovery movement. However, inside, she still felt shrivelled and crippled (G:84:16-18), and (G) felt psychotherapy would help to address this.

Engaging with psychotherapy became the second phase of recovery

(G:83:1) the second stage which was the more, in some ways the less dramatic, but the more meaningful, was my contact with psychotherapy... (G:86:1) the work of Bowlby and Winnicott I think informs what he does, but also like the Rogerian core principles as well.

Initially, what was helpful was being able to talk freely without having to engage with the framework of diagnosis.

(G:108:4) in therapy we spent relatively little time talking about the voices but a *lot* of time talking about me and the way I sort of feel about myself.

This was like being able to open a door behind which so much bad feeling had been trapped.

Feeling of being trapped and unable express pain prior to recovery

(G:99:16) I felt for years that I was just sat in this stark, fetid room, just screaming and screaming and screaming and in some respects I'm probably still in that room, but the door is in front and it's wide open, whereas for the first, at least, 25 years I didn't even know there was a door in the room... (G:100:1) probably just before therapy I could see the door but didn't know how to open it. And therapy's really helped open that door.

To make full use of the psychotherapy, (G) felt she had to come off medication.

Coming off medication meant participant was able to experience difficult feelings, and then make sense of them

(G:119:2) I felt that... if I wanted to negotiate this strange subconscious world in a constructive way, then I sort of needed my wits about me to do it, and these drugs were so sedating and stupefying, and had all sorts of unpleasant side effects.

As with many of the group participants, in coming off medication, initially her symptoms worsened.

The voices were affected by coming off medication

(G:123:4) this more childish, quite vicious, spiteful voice - felt that I was easier for him to control when I was very, very sedated. So he almost had a vested interest in me - as he perceived it - for me to be on medication. And he didn't like the idea of me becoming more active and more astute.

At the same time, the painful experiences that (G) was exploring in the therapy seemed to make things worse.

By addressing underlying issues, therapy initially made things worse

(G:90:1) it was really hard to begin with. I remember my mum and my sister both sort of gently suggesting maybe this isn't a good thing because it seemed to be making me a lot worse... (G:91:1) I just became really, really upset and just, I think because I finally had a real awareness of how profoundly I was hurt and I think I'd worked so hard not to acknowledge that.

However, (G) thought it was helpful to persevere beyond this point, because (G) now realised that these feelings were attached to bits and pieces of memories that were coming back together now that she was finally in a safe enough place to deal with them (G:96:1-6).

Going back into past trauma helped healing process, but is a work in progress

(G:95:6) Actually, part of that was just going through my relationship with my mum and dad. Because in a way I'd sort of never really acknowledged, or understood how much that had hurt me. And... and then the year after that - and this is still very much work in progress - is stuff around the abuse. And that's like hugely difficult, and you know, if I gave this same interview in a year's time I'd probably give you quite a different account on how that's worked out.

Through this process,

Therapy helped gain greater insight and realisation that bad feelings were not innate

(G:18:2) I think internally that was something that's quite hard to try and come to terms with in that my mum's sort of lack of tactile affection was very difficult for me... (G:18:5) *(through therapy, participant begun to understand)* that a lot of feelings I had about myself weren't innate, it was something that I'd acquired almost as a result of circumstances.

As part of this process of understanding how things fit together internally, (G) developed an image of her mind having been split into separate rooms.

By addressing underlying issues, therapy helped internal relationship to trauma develop, which changed the way the symptoms presented

(G:108:8) we sort of had this idea - my therapist and I - it's not a particularly original metaphor, but you know, a house and in the rooms, there's a person in each room and all the doors are closed, and it's trying to open up the doors, or like at least install some telephones or something...

Being involved in a therapeutic relationship with someone who was willing to be open and authentic helped (G) to be more authentic with herself. This was important, because she felt that the internal boxes were one way of managing internal divisions concerned with persevering a separation between good and bad images of herself.

Therapy helped participant to reduce the split between trauma and false, protective coping self

(G:104:1) What I have learned how to do is to hide really negative emotion, and to try and keep other people very happy by developing this very strong part, which I needed to survive my dad in a way. This is a part that's very good at reading the situation, to try to defuse an explosion before it occurs... (G:105:1) I think in my therapy relationship I spent a very long time just being a pleaser and being very polite and obliging and if he said something that I didn't find very helpful, or didn't think was relevant for me, I wouldn't tell him... (G:106:1) And I think he, you know, would sort of say, "You don't have to keep me happy." (G:102:5) I think it will be a breakthrough for me in some ways if I can be angry with him, because then I just really let go and show him more aspects of myself, because it will be a more authentic relationship in a way... (G:103:1) I still hold quite a lot back because intimacy's something that's been very, very hard for me. And being able to sort of really attach to somebody means showing these undesirable aspects of yourself in some ways.

Overall, (G) felt that psychotherapy helped to bring about a transformation in her.

Therapy helped to promote growth and independence, and develop a sense of potential

(G:4:1) certainly in the last few years... I've been able to achieve... this sense of transformation. So not just going back to how I was before the breakdown, but more than that, a real sense of growth and potential and opportunity... (G:132:1) in a way that's sort of internalising my therapist as well because that's what he would say to me, and he sort of helped me internalise my mum's reassurance as well. 'Cos in days past I would sort of ring up my mum like at least twice a day 'cos I could, I just had no internal ability to reassure myself. I had to get it from outside, and I'm much better now at just doing that for myself. So I'm nowhere near as dependent on external support.

TGv) Recovery

As we saw above, (G)'s recovery began when she was encouraged to explore the meaning of her experiences. Beginning psychotherapy some years after this helped to deepen the transformation that she experienced.

Recovery is a process of making sense of experience and integrating it

(G:3:8) the recovery response is accepting, and integrating and understanding the emotional meaning of your experiences and a big part of that for me was... sort of understanding the psychosis not as this independent - or causally independent - biologically induced disruption to my life, but rather understanding it as significant, meaningful, interpretable experience that was formative in terms of giving me insight into all kinds of social and emotional problems that I needed to deal with. And it was by dealing with those problems that then in turn helped me in turn understand the so-called symptoms, or I would call them coping strategies a lot better, and then in turn find real healing and growth and transformation.

Part of this making sense was a kind of mapping of her internal world and understanding what aspects of her experience different aspects represented.

Subsidiary voices were all related to experience or unexpressed emotions

(G:56:1) it's hard in a way to clearly identify them, because they're all sort of tied up in ones that remained and changed, and have altered over the years, but for example one of them represented my grandmother who had died when I was 8 years old of a stroke, and who I'd always been very, very attached to. And this voice would sort of tell me to kill myself and be at peace and to come and join her... (G:57:1) I heard a voice of a nurse... this is somebody who when I self injured... (G:57:8) sort of poured neat disinfectant over it and started to scrub

and it was... it was like being flayed, you know, it was... appalling pain. And just her sort of... yeah, just disgust and just you know objectification of me, that I was almost less than human in a way, and was unworthy of just basic compassion. And I would hear her voice, you know, "People like you, people like you."... (G:58:1) some of them would be directly tied to people that I'd encountered in real life. Most of them were sort of more abstract and I think represented more emotions than people. So one voice was a child's voice, which was very troubling, which would scream and cry and was very angry with me. And would be, "Why did you leave me here, you left me here alone, I hate you I hate you. You left me here." Then there would be the voices of other children - also very angry with me; angry with each other.

This transformation is illustrated graphically by the response of (G)'s most feared voices to the process that was going on in her during this recovery.

There was a main voice, which had a distinct character

(G:47:2) There was this figure of just immense fear and terror ... and just agony almost, all tied up in this one voice and it would ultimately take on this really grotesque visual manifestation. So there was a man, sort of immensely tall, swathed in black, black hat, black cloak and was very shadowy and nebulous and the only thing about him that was clear was instead of a right hand, he had a hook, sort of like a butcher's hook and this figure would sort of appear and sort of like almost slither around the ward and I would turn around and he'd be there and then he spoke in this very grating - and it was a human - voice but it almost had a sort of mechanical overtone to it as well, and it *sounded* frightening. It would growl and when it did speak it was hugely articulate and fluent, and I'd been sort of studying *Paradise Lost* at the time and it would sound almost a bit like Satan, the character of Satan in Milton, you know, but *so* powerful and intimidating and domineering.

The voices had a schema of interaction

(G:58:7) And the voices would sometimes interact with each other, but all of them were consistent in that they were all afraid of this dominant voice. And sometimes they would get together and whisper, so that he couldn't hear them, but then if he instructed them to behave in a certain way, then they would. And they were very fearful of him and sometimes they would disappear because they were so scared of him, and didn't want to be around when he was there.

Through understanding the most fearsome voice, participant was able to understand the damaged aspect of herself that the voice represented, and in turn, this made the voice more benevolent

(G:60:4) over the years that voice (*the main voice*) changed hugely. It was almost like Doctor Who in a way in that he would like regenerate almost every year. He'd disappear for a bit and he would come back in a slightly different form. And visually disappeared completely and I haven't actually seen him or any image for many years now. But every time he came back he was more benevolent. And he became calmer and calmer and kinder. Until it sort of got to the point where... he kind of left in a way actually, but didn't leave. It's almost like he became more integrated into me, I guess you would say... (G:61:1) he was the voice that definitely caused me by far the most problems. But he was also the voice that held the real key to the healing in him as well... (G:61:14) he was really in some ways holding a lot of all of that together and that was one of the turning points in my recovery journey was learning how to cope with him and to understand him.

The most fearsome voice, which was the main voice, represented the participant's damaged sense of self

(G:48:1) how I ultimately came to understand him was that he was a hugely amplified version of that original voice that reflected my own emotion. So I think of all of them that voice really represented me. And I think he represented the aspects of me that identified with the people who'd harmed me. So the part of me that felt, "You deserved it, you asked for it, you're bad, you're dirty, you're flawed, you're destined to suffer, your whole life is going to be cursed." You know all this kind of thing, all this awful, awful negative emotion. But ultimately he also represented the part of me that had been harmed the most and in that respect, he needed the most care and compassion. But obviously I responded to him with the most fear and

resistance, and you know, worked to the point of exhaustion to try and blot him out and not acknowledge him.

As a result of this transformation,

Recovery promoted new relationship between self and voices, which now tend to be helpful (G:2:5) what's changed is the way that I relate to them because I understand so much better, and I feel like there's a relationship between me and my voices that's quite good and constructive... (G:129:2) in years past, they would have probably been offensive to you or me, or threatening or menacing in some way. Today it would be far more likely it would be helpful, they might remind me of something I've missed. That would be very common, they might say oh you should- hypothetically they might say, "Oh Tom might be interested in x y", and they would suggest things to tell you.

Voices still express anxiety, but participant now understands this as an expression of underlying anxiety and is able to work through it

(G:131:1) I was getting really stressed over this particular aspect of my PhD that was giving me some problems, and the voices will get panicky. And because my default reaction is to be self-critical, then the voices will do that as well... (G131:7) And you know that's basically *my* feelings. So my reaction to that now is, again, to try and comfort that voice, which represents comforting myself... (G:133:11) Or that little, that shrivelled self almost. That's the part that's being cared for and comforted.

Participant C – Sample interview transcript

- So the title of the research and this is the question that I'm looking into in this piece of research is, 'What are the psychotherapeutic experiences of those with a 'schizophrenia' diagnosis?' So I guess the core components there are the diagnosis of schizophrenia, experiences of psychotherapy, and whether the psychotherapy has been helpful or unhelpful.

0.47: (C:1:1) Cool.

- What is your current diagnosis?

0.48: (C:2:1) I've got a few – schizoaffective, so the mixture of schizophrenia and supposedly bi-polar, although, yeah I've had the diagnosis of schizophrenia and it tends to swap between the two, depending on which person speaks to me. I also have dissociative disorder, in inverted commas, some people say that's dissociative identity disorder and that's probably gonna be my new diagnosis, as well as schizoaffective disorder and also occasionally I get diagnosed with personality disorder, depending on how people feel about it. So I carry a bag, although I'm not currently diagnosed with a personality disorder.

- So that's an awful lot of different things and potentially conflicting things all in the same bag.

01.30: (C:3:1) Hmmm. it's kind of, I think it depends on the person who's speaking to you, the glasses they're wearing, so the psychiatrist will see me very much in terms of having a biological mental illness that, because I supposedly have primary delusions, i.e. I believe some really weird stuff and have very extreme experiences and my voices are third person stuff, then that means I've definitely got a biological illness and they'll see that part of me, but I also won't tell them about my emotional side because I don't wanna be diagnosed with personality disorder, so when we have those communications we talk very much in terms of the illness, or we used to at least. I've changed that myself now a bit. But the trauma therapist or the trauma psychiatrist or psychotherapist will see me in terms of things that happened in my life and then rather than see the biological illness, they'll see the sense in it and see it more as dissociative experience. Whereas the psychiatrist will then go "Oh you've got emotions and traumas, that means you must have a personality disorder, because it's impossible to go through that trauma without having a personality disorder." But with psychiatry both of those diagnoses means that I'm not open to psychotherapy because I've got schizophrenia and also, yeah, as well as schizophrenia I'm personality disordered sometimes, so little point in working around that.

02.52: (C:4:1) But obviously the trauma person would then go to me it's important to have therapy, so it is massively conflicting and has been intensely confusing while I've been going on the journey, I think. Yeah, no it has been confusing. And you find yourself responding to the people that are then looking at you through those glasses in ways that I can see, like looking back, that I've kind of bought the delusions and hallucinations to the psychiatrists and stayed away from the trauma and brought the trauma to the trauma people, and actually now I've started to talk more about the voices to them, but it's almost like what they want to hear is what frames your

experience when you're with them. So it encourages you to split things off I think a bit more than is really helpful.

- There's also something dialectical about the diagnosis itself. So in response to receiving a diagnosis, you might then behave differently or reveal different things to different people, depending on their diagnosis was and what the implications of that is.

04.00: (C:5:1) Yeah, even within sort of just in general as I say without, I mean obviously with psychiatrists I have to be very careful or I feel I have to be very careful about what I tell them or what I don't tell them. In truth that was more me a year ago than me now 'cos I've started to make more sense of my own things, and I can bring more of the emotional stuff to the psychiatrists, but before it was, "Ok, I don't wanna be labelled BPD so I'm not going to talk about feeling unstable, I'm not gonna talk about this other stuff", because I don't want that diagnosis, so it shifted what part I was willing to share with them and the language I use. But even with like peers, sort of the Hearing Voices Network, you even have a shared language that you talk about experiences within that, so it's like living a triple life. With kind of the trauma stuff, which is spoken one way to this therapist, or to this psychiatrist, minimised or not gone into at all with a medical psychiatrist, and used in a very different way with the Hearing Voices Network, and then you've got the voices being seen as different things in all three and it's yeah, it's not even a dichotomy, it's just lots of sweating really which, if you're kind of quite confused about who you are anyway, can just make you feel you're not quite being yourself with all these three different, or four or five different groups.

- You might need to add multiple personality disorder to the list.

01.30: (C:6:1) That's my latest one! Yeah, dissociative identity is the new version of multiple personality disorder and that's through- 'cos if you look at kind of my experiences through that kind of trauma related stuff and the dissociative experiences I have, that's the diagnosis you'll come up with. Which is just, I've just gone through a load of lengthy assessment process, at the Maudsley's Trauma Clinic and that's what they've come up with, so yeah it's kind of funny that I'm now holding some of the most hardcore psychiatric diagnoses, yet I can work five days in a week and I'm actually pretty sane. It does make- but it's not like I'm, back in sort of five or six years ago, I would have jumped at that diagnosis and not kind of changed the way I acted based on it, but changed the way that I understood myself based on it. So it would have re-framed a lot for me and I believe that these people who gave me this diagnosis would have some control over the way I see myself, but I'm not doing that now.

- Why would you have preferred that diagnosis?

06.30: (C:7:1) I wouldn't have preferred it actually. When I got the diagnosis it freaked me out chronically. The first person that mentioned it to me I was like, "No, that's not me." 'Cos it felt even more hardcore than schizophrenia. It felt like with schizophrenia I've got the Hearing Voices Network, that many people are diagnosed with that, and it's almost like even though I don't believe it exists, there's lots of other people that have been diagnosed. And also don't believe it exists, and there's a

kind of common factor. I was worried about getting dissociative identity disorder diagnosis because suddenly that separates me from the Hearing Voices Network and it's like, "What do I talk about - my alters?" There's a whole language used with that diagnosis that I don't feel comfortable with. And, so yeah, it freaked me out.

07.06: (C:8:1) But yeah, I think what it would have been is back in the day if someone told me I'd got that, I'd have looked at my experience and gone, "Ah, these are alters, this is true because they're experts telling me this", and it would have changed how I saw my internal world. Whereas it's almost like now I feel able to go, "Well that's a way of seeing it, and I do believe I have aspects of my personality and my identity and this is where the voices are. And I do have memory blanks, and all those kind of things that you get, and those sort of aspects do effect my behaviour and I there's things that I do, especially when I'm re-living flashbacky traumatic stuff that I don't remember, which is how come I get that diagnosis I guess, so it does massively impact on me. But I believe that, that's not about a label, it's about - of course I've been traumatised, that's my way of boxing things up and it's going to come out when these things come out and it's just it's a - while I'm starting to make sense of it, that won't always be me, it will all kind of integrate again I'll feel more whole. And I feel comfortable being in the voices field, as well as the dissociative field, 'cos I don't think the labels really - I think we're talking about the same kind of thing, it's just the label itself isn't powerful like it used to be.

- How would they been seen as being distinct?

08.20: (C:9:1) Distinct, separate, um... I think, people with schizophrenia, have spent a lot of time, I've spend a lot of time trying to tell people it's not split personality, this is an illness, or it's a response to trauma, but we're very (*inaudible*) "This isn't split, this isn't (this) weird, crazy thing over there. So they've been kind of going, "Yeah, no, no, we're not like them", and like the people with dissociative identity disorder have been going, "Yeah, but we're not schizophrenic, this is trauma related, this makes sense and at least we're not like those crazies." And it's like they've developed separately. And it's really weird - people went to a conference and I found it really challenging, it was a dissociative identity disorder sort of day, at Holloway. And it was fantastic 'cos I recognised a lot of these other people and their experiences, but also frightening because they spent a lot of time trying to get it medicalised, but also separating it from schizophrenia and, yeah, I don't know, as someone who supposedly crosses the boundaries of their- it seems artificial and stupid to be trying to distinguish it. It's just human experience. And we all have different aspects to ourselves if you've come through some extreme trauma, then that's going to be a bit more extreme than the divisions, or the contradictions in that, but you know, some of those aspects might have voices, why try and label it? Why should that indicate what support you get as well, 'cos like now I'm being seen as dissociative identity, I've got a dissociative identity therapist who's great, but doesn't get the whole schizophrenia thing and she'll look at it from that perspective and even though (*inaudible*) it's dividing it. We do talk about my beliefs and we talk about my voices and all that stuff, but it's very much from a dissociative frame.

- So you work with someone specifically from that perspective then.

10.20: (C:10:1) Yeah I do now. This is my latest. It's the most productive therapy I've ever had really. My previous, the year before I was working from the other basis of psychosis and schizophrenia with the B**** Centre and it was the most un- it was ok, but it was like, she was a social worker, the reason I was paired with her is that she's got psychiatric experience as well as therapy experience. She was a trainee, which wasn't a great idea actually because I think she didn't now what to do with me 'cos I seem very ok, I can talk about it all very insightfully. But yeah we just realised that after a year we hadn't got to the heart of anything really.

- How was she trying to work with what you were bringing?

11.04: (C:11:1) In a way she was, I felt like she wasn't, which sounds kind of horrible... I'm trying to get back into the thing (*remembering the therapy*). We'd talk about the voices and what they said and we'd talk about – there was a time when I was feeling very paranoid, and like J*** (*partner*) had been replaced and my job was kind of like a, it wasn't really my job, this was part of the experiment so it was part of the alien stuff. And I was feeling quite distressed and I do remember talking to her about that, but we didn't really, it didn't go anywhere, it was almost like it just hung. It was like, "Wow, that must be really scary!" and we talked a bit about it but we didn't, yeah, I didn't feel that we went into it. Certainly, after it had passed, it was almost like then it went and we didn't have the thread going, "Why did that happen? What's that say about how you're feeling...?"

- There was a holding back from something?

12.03: (C:12:1) Yeah, I think so, maybe she was anxious about going into it, of what would happen, because, again, she was coming from the perspective that there was an illness there I think, even though she understood it psychologically I think maybe she was a bit split as well as me.

- The fear of you becoming iller?

12.24: (C:13:1) Yeah, and that came up as well, how am I going to manage, you know, these symptoms and the word symptom was used, which I don't like. And I think from my perspective, 'cos I've been involved in psychiatry, I'm really susceptible to power stuff – that doesn't make sense. I really struggle with power relationships within therapy, so I'm used to having psychiatrists that can section me and give me medication and not challenging and be very passive within that for fear – that's my childhood, and that's where it is now. So in therapy I would do things like I wouldn't ask to use the toilet, 'cos it's a horrible boundary cross for me to use the bathroom in the therapist's house. I wouldn't like to challenge her about money, so I'd get charged for sessions where I was on holiday. I wanted to say, "But you know, yeah, you take holidays too", and I wanted to question some stuff and I wouldn't be able to. If we didn't get to process stuff and I thought I really need to go into it, I wouldn't feel able to articulate that.

- Would that have been useful in the work itself to challenge those things?

13.27: (C:14:1) Yeah I mean I've got a really challenging relationship with my current therapist, that I can challenge her and I have. We've had - not arguments - but

disagreements and I will use her toilet and I will talk about money and I will say if I think she's said something that I've found quite hard to listen to or quite disrespectful, or the language that she's used and I'm able to do that, and that's brilliant.

- How does that change things being able to challenge something?

13.55: (C:15:1) Erm... trust I think. It's a big thing trust. Like, something I'm going through in the therapy at the moment, is, I never realised - and I think this was the problem with the old therapy - on the surface I trust people and I'm really quite, get along with people quite well, I'm very reflective about my experiences and you know you'd think I'd be easy to therapise, you know. I think therapists fall into the trap of thinking what's on the surface is kind of there, and I sound like I'm doing it, but what I've noticed through this new therapist, and kind of actually going into the relationship I have with her, I don't trust - my voices don't trust her either, even my sort of child voices, they find, yeah, I'm massively sensitive to any inconsistency, any sign that this is going to disappear. And trusting is dangerous and trusting someone in a position of power, 'cos of the childhood trauma, and it's, yeah, I've been in therapy for over a year now and I still don't trust her and she knows I don't trust her. I *like* her and I kind of, I feel, I experience her as really unstable - she feels very unstable to me and she feels like she's contradictory and all this stuff and....

- So there's something not consistent?

15.18: (C:16:1) Yeah. But I know she's consistent as well, she's as consistent as a human, but at the same time I'm respectful of the fact that she's allowed to have days where she contradicts herself 'cos she's human. But it's, yeah, I'm pretty sensitive to that. If I'm able to challenge her and kind of say when I think she's being inconsistent or when she says I'm doing really well and I'm actually doing really bad and she's worried about me and that happens within a session I'm just like, that sets me off, that sets my voices off and my voices start talking about her a lot. But by being able to talk to her about that and how I experience it then, it's slowly building a little bit of trust, because when you can't challenge someone, you're like, if you do the wrong thing, if you're the wrong client, if you're kind of yeah, if you're not good, it might end. Or they might hurt you or something. Whereas with a therapist you can actually be really open with, I think the more that I and my voices see that she doesn't do anything terrible to us, no matter what we kind of bring, the more I'll be able to trust her. And once I can trust her we can go a bit deeper into some of the stuff.

16.25: (C:17:1) But yeah, I never thought I had trust issues! (laughs). Going to therapy has made me realise that I'm pathologically - no not pathologically - but I just have major trust issues. But specifically with people in a position of power, not with like J*** (husband). Absolutely fine because he actually fell asleep on me so he go underneath my trust issues 'cos there is a kind of, yeah, it's more of a balance.

- What kind of things would the voices say in response to the sense of not trusting?

17.00: (C:18:1) Yeah, (laughs) different ones. I've got lots of different voices that get, there's the easy ones are the ones that obviously are not going to trust her, they're the Not Yets. And the Not Yet are ones that I feel are very much representations of my

abuse – abusers - and they're the ones that are very nasty to me, but to her they're kind of, they're really vitriolic, they're basically, yes, say quite nasty things about her, but also they're like saying that she's also going to hurt me and she's just tricking me, that this is kind of, if I say stuff, then they will get me and it just, yeah, that it's. I have to edit, 'cos I don't – it gets (laughs) yeah, it gets a little bit chaotic. They're very much threatening. Threatening her, threatening me if I talk to her then they're threatening. That's, yeah, that's actually not that hard to deal with. It's horrible and they're the ones I'm most afraid of, but it's not that hard.

- Did you call them the Not Yets?

18.04: (C:19:1) Yeah, that's my name for the group, which is kind of the ones I don't want to deal with yet. So it's a pushing away strategy that I've got, 'cos they started talking to me about two years ago, very shortly after starting the first lot of therapy and I think I have had them occasionally, but more in earnest and I think I was, yeah, I had this horrible experience in therapy where - well not in therapy - well before a therapy session where I kind of was in bed and some things were happening to me and visual kind of hearing-y stuff that I won't go into, but it was, yeah, it was stuff that was like flashback-y I guess, but I experience my flashbacks a lot as things that are happening. They're not your stereotypical flashbacks I guess, I hear and I feel and I can't move type stuff. Which sounds like a flashback, but yeah.

- They feel in the present.

18.56: (C:20:1) Yeah, that's it. And the Not Yets started talking to me for that and that's something I took to therapy and that again didn't go anywhere. I think that's why I felt very frustrated with that, 'cos I think so much of that stuff came up and it didn't get- nothing. Actually what happened is I then stopped my relationship with my husband in a physical way because all this stuff was coming up but not being dealt with which is one of the reasons I changed therapists. Yeah, because you have to prioritise your relationship.

- And it wasn't able to be dealt with in the therapy it sounded like.

19.29: (C:21:1) Yeah it just came up because of- we weren't even talking about trauma, it was almost by the process of going near that stuff it started to come up. But yeah they first came up and I kind of didn't call them Not Yets until I tried a male therapist after that therapist - I'm a therapist hopping person (laughs). I spent a year with the first therapist and then I realised I needed someone different.

- At the B**** Centre.

19.50: (C:22:1) Yeah, I got really disillusioned with the B**** Centre because I was like, "You shouldn't have placed me with a trainee and, even though I seem very nice, it's like actually my issues probably need someone with a bit more experience. So I found an experienced therapist, but a male therapist, who taught at the B**** Centre, and I found it myself, I had control of it that way which is great, except... And that was cool 'cos I could talk to him about some stuff and he did really look into things with me - I had about four or five sessions with him. And that's where I called them the Not Yets, because that just helped me put them in a, in a sort of a box over there

that I needed to trust the therapist before I could even talk about them, type of thing. And I needed not to feel they're as powerful as they are. Or as I feel they are. I needed to change the power of them a bit.

20.41: (C:23:1) But with him it was really hard because he was in this long thin room and again I couldn't challenge him about this at the time. But it was a long thin room and there was a little kind of therapist type couch thing, not like a long couch, like a Freud couch, but just like a cute little sofa which I'd sit on and then his chair would be opposite me and then the bookshelves and door sort of a long way down and to get to the door I would have had to push past him, so I felt very trapped. And again, my child voices, which also kind of comment a lot on therapy, felt *very* stressed and got very tearful and very kind of scared. And then that kind of went after therapy, I struggled a lot. And in therapy I struggled with zoning out a lot and struggled to kind of stay around in a session and I kind of realised that actually having a male therapist that I couldn't really easily get out of the room in was a slightly stupid idea for me.

21.42: (C:24:1) And, but because of my inability to kind of talk about problems or any negative stuff with the therapist, I couldn't tell him that and so I kind of realised that I needed to get a female therapist. And also a different set up of the room. So we ended it very nicely. I did explain to him that I needed a female therapist and he was cool with it. And yeah the first therapist I didn't tell her that she was crap and she was a trainee and she should go back to school, which isn't true, anyway, I sort of explained that I, she knew that we hadn't got anywhere, I knew we hadn't got anywhere, and it was really good because what she'd helped me do was realise was that now I feel ready for the therapy, but that I need to find somebody else to have that therapy with. So I've been very careful with my endings with them, which is a bit strange.

22.30: (C:25:1) Yeah, I found separately this – (I) went to the P***** Centre For Dis-Association, to get a, 'cos one thing that had come up for all the sessions was that when things get hard I don't remember the sessions and I don't, I'm not really, yeah, I'm not really there for some of it and I thought ok let's look at this dissociation, then get an assessment, and get some ideas for the therapist that might not get freaked out by that, and got the current disassociative therapist type person. And that's probably not even answering the question, I'm not sure what the question was anymore. That's right, what were my voices saying about my therapist, yeah.

23.11: (C:26:1) Erm, it's weird child voices and these are the ones that are more like aspects of my identity 'cos I can kind of place them. Blue the little one really likes Orrick but is also very scared of her, but Blue's scared of everybody, so in a way she's like she really wants to see her but and I'm struggling between sessions she wants to connect with her, but then also, yeah, she also goes away and gets frightened, and kind of doesn't wanna, yeah doesn't wanna go as well. And then there's a teenage one that really hates it, (*laughs*) which is understandable really. Alfie's just like yeah, she really, really hates therapy and hates talking about all this crap.

23.56: (C:27:1) She used to try and get me to stab myself actually at the start of therapy for the first six months. I'd get images of a knife sort of (*mimes stabbing*) in my middle or something like a spear knife type of thing, and of me kind of like stabbing myself. I had a real impulse to. And also burning, I'd get a lot of burning

sensations in my body and it felt very much like this voice, Alfie, was trying to burn the children for talking about things. But I could actually feel the fire. Again, I know it sounds a bit crazy but yeah it created a lot of chaos I think is the thing. I can understand how some therapists would be like – “Aaaaaah this sounds like it’s setting off more than I can handle here”. And it was more than I felt I could handle at times. But yet it wasn’t because I’m here and I dealt with it and I still get that sometimes, but it’s like almost talking is dangerous, and talking *has* been dangerous in the past. And I’m going to be frightened of talking and that bit of my voices is *me*. So they’re gonna be angry or frightened and they’re gonna pick up like things that I don’t think notice, but obviously I do in a session, where there’s like a picture, a picture that was one from my mum’s house, which she just randomly has - same frame and everything which is really, really weird. After three weeks of seeing that there and feeling really weird, I actually told her about it and she took it down. And then the next week she forgot to take it down and I didn’t notice – well, yeah I did notice - but I didn’t notice, and then the voices were talking about it afterwards and I had to kind of email her, and see if she still had it and she was like, “Yeah, sorry I forgot about that”. And I was like, “It’s cool”, but to me - part of me - that’s like a terrible violation. Yeah I know sensibly that isn’t and it didn’t cause any major ructions ‘cos; ok she’s forgotten and I’ll be able to say it, but it’s like, yeah they talk a lot about what happens in the sessions as well. And also whether I should contact her outside of session time, ‘cos I don’t want to and she wants me to and some of my voices want me to and some of my voices really don’t want to.

26.16: (C:28:1) Therapy’s confusing. Therapy for me is like having your insides ripped out and it hurts so much, it hurts more than I’ve ever, ever thought anything could hurt, looking at your stuff as having meaning hurts it’s a lot easier to talk about it in terms of alien conspiracies and kind of - one time I went saying I’d kind of started to believe that I was, *Bladerunner*, yeah, after something I’ve been in therapy for maybe a few months, I kind of went, I’d started to believe that I was one of these, I can’t remember the word, but yeah these *Nexus 7*, whatever it is. Which basically meant that I didn’t have a history and that I was basically made and all of this stuff that I was remembering, all the bits my voices were remembering weren’t real and I was just given those memories and that I’m not human.

- They had never happened to you.

27.21: (C:29:1) Never happened to me, I’m not human, this is not, and I’m also going to die quite soon because, you know, there’s a time limit on this stuff I’m not real. Talking about it now I can see it makes so much sense ‘cos I didn’t want it to be real and I have a very metaphorical kind of brain, so some people might be, “*As if* this is happening”, for me “*This is* happening”, and it gave me a lot of comfort actually, but yeah it’s really useful.

- Was that at the point where you said that when you began that particular juncture of therapy when you were starting to feel very paranoid: “Is this my partner, is this my job?”

28.07: (C:30:1) Yeah, I’ve had that very sort of on and off and I think with the first therapist, that happened quite a few times, but never went anywhere. With this therapist when that happens - it still happens sometimes - she’s a bit more challenging

actually, she respects that I might need to think that at the moment, but she's like... (*thinking out loud*) How does she handle it?... We talk about it, but then she kind of goes, "Well, this stuff is hard, you might not want, people might have been very duplicitous in the past". So with the husband thing she might talk about how in the past people haven't been what they say they are and it makes sense that I'd be worried about stuff like that, and with the thing, she would probably say, "It makes sense that you wouldn't want to, yeah, this stuff is really hard, you wouldn't want it", but she doesn't let me get lost in it, which is actually useful because it's not like these are temporary things for me, just like fleeting thoughts, it's the sort of thing that once you start thinking about it, it gets deeper and deeper and deeper and then it's not like you go into – what they call - psychosis, because I think psychosis isn't always a useful term, but it happens over a period of time as I get deeper and deeper into things, and what happens now I suppose is I start to get that way, start to really think about these things and I start to come back to the experience and go, "I've had a shit time". And it makes sense that I try and escape it and try and make it not real. It's ok if I wanna make it not real for a while, but I never lose the fact that it *is* real 'cos I'm saying it's ok if I wanna escape from that a bit, whereas before I'd escape from it without knowing I was escaping.

- And so being able to root it in experience and connect it to experience, it stops something sheering off and detaching altogether. Because there is a logic to it that you can come back to.

30.20: (C:31:1) Yeah, once you've seen it, it's almost like - it's quite emotional actually. It's kind of like the Matrix. Once you take the pill, you can't un-see that. You can't un-see this different world and, as much as I'd like to - and sometimes I would like to go crazy again because it'd be easier, it really would be easier sometimes - you can't un-see the sense that you've found in it. I can kind of have a break from the sense and maybe give myself a bit of respite with psychosis, but I can't ever go back.

- So the craziness, as you were putting it, as a break is detachment from some kind of knowledge. Taking yourself out of the experience.

31.12: (C:32:1) That's it. It's losing the meaning, 'cos the meaning is overwhelming and I wouldn't have created these worlds inside myself as a child if it wasn't terrifying and horrible and if I didn't need those worlds. And occasionally in the future I might need those worlds again for a bit. It's like...

- Refuge.

31.30: (C:33:1) Refuge yeah. And again, but it's not a fun refuge, and that's the problem, it's like you'd imagine if I was creating this as a refuge it'd be full of flowers and bunny rabbits, but actually it's tortuous it's not fun. I feel very powerless, I feel that – yeah I don't trust reality, and I just get very stuck, but yet weirdly enough compared to the reality of why I feel powerless, that's better, it's better to have aliens and monsters and kind of robots and things rather than real people and real events that I don't want to think about.

- I guess that seems an important question actually. That if one was going to create a refuge from something very difficult that had actually happened, why would it be a tortuous refuge rather than one that seems like an escape?

32.24: (C:34:1) (Laughs) I don't know if I've just got bad imagination. Have you ever watched Sucker Punch? It's a movie that really resonated with me, it's kind of, it was on at the cinema a year or two ago. A year ago. Worth watching if you're interested in trauma dissociation, 'cos it was made by a guy and it was kind of meant to be a bit like male fantasy type things – girls dressed up in things, fighting stuff with guns, but beneath that it was really powerful because it was showing this girl was in an asylum because of a traumatic event that had happened and she split off from reality, but the reality that she split off into had traces of the asylum in it. So the power relationships, all of that stuff, were still there. And the being objectified and the horrible things that were happening were still in the fantasy. And there was another level of fantasy and it's almost like, you take what you've got, if you're feeling... As a child, I guess I felt really vulnerable and really wrong, really bad and terrified and yeah, no control, and that's all I knew from quite a young age actually. And so yeah that got, that's what my world was like, but the thing- what I did change I think is all of that stuff was familiar, so that wasn't weird, that wasn't necessarily what I was escaping from. What I was escaping from was the people who were hurting me, and so instead of having people who were hurting me as being people, they became monsters or aliens or *things*, separate.

- Because to think about them as a person who may share certain human attributes and all the rest of it. But who also may be invested with elements of trust, or love is quite difficult isn't it.

34.18: (C:35:1) Definitely, that's it, I guess I did create a refuge and the refuge was not having these people. It's like Blue, the little girl, her view of the world, or at least her internal environment that I have and where she feels most safe is just in blackness, like in darkness and doesn't like open doors and doesn't like lots and lots of things. Doesn't like connecting with any other people, or even objects, because that's not safe. And it's like, so for her the refuge is just darkness. And it's like, yeah I can see that, so I guess refuge is created from what is the most difficult part of that experience, whether it's people - like I have Tommy.

35.01: (C:36:1) Tommy is the only boy, the only non-nasty boy that I have as a voice and as an aspect of self. He counts, he does patterns and traces the environments – and this is really interesting in therapy actually – this comes up quite a lot, 'cos the more stressed I get the more I do little patterns as a safety strategy. But what I never realised that I do until looking at it, is I will trace the difference between objects. So in this room my natural pattern would be like that, never around people but always around objects. And what I know now is that was a way of just ignoring people and the things around me, but focusing on the only bit that was safe. And it's like yeah... it's really creative and I've got quite a lot of, I think one of the best things I did was do a conference where I was talking about voices and medication and actually honoured all of my voices, even the abusive nasty ones, as things that have - as people – as things that have saved my life really, even the horrible ones have got a purpose. I'm still working that one out to be fair.

- The Not Yet voices.

36.16: (C:37:1) Yeah. I don't like them, don't want them I'm a little bit afraid of them - shouldn't say that - I work with people on how to change those power relations. In all honesty, I still really struggle with them. Yeah, but I also know, it's that sense, that feeling you, 'cos I know that they're there for a reason and they're not the abusers and they're not even (incomprehensible), they're about me having kind of taken some of that in. They're representative of the abuse; they're not the people that hurt me. So – yeah they're trying to keep me safe in their own way. Or I'm trying to keep myself safe by not talking about these things and by not sharing it. So yeah, once you see it it's hard to go back from that.

37.01: (C:38:1) And I don't think I'll ever go crazy again. Not properly. I think I might go through periods of psychosis to get away from all this, but I don't think I could ever spend eight months in hospital and believe I was schizophrenic. I think schizophrenia's irrelevant. I actually think it's colluding with the abuse, I really passionately believe, really believe that if we talk about schizophrenia we're locating the problem with an individual and we're neglecting society, whether or not they've been through the traumas that I've been through. There's been stuff that's happened to everyone that gets that diagnosis and by saying it's them, it's biologically wrong. Even if you're trying to help them it's just reinforcing the abuse and the trauma that they've suffered their whole lives.

- Because it takes the other people who may be connected to a particular experience out of the equation.

37.48: (C:39:1) Yeah.

- Which can happen in abuse in the first place.

37.55: (C:40:1) And also it's your fault. You're being abused because people think you want it, you're bad, you know, yeah. It's that you're the problem, not the abuse. It's, you've done something wrong, and you feel that very keenly as a child and I grew up with this sense of me being the monster, that's why I have Monster Girl as one of my voices, or Alfie as I call her now, 'cos I gave her a different name. Naming the voices has been really helpful to me and this is what the side that I helped (Participant F) with, naming his and changing the names 'cos names are powerful, and you and the voice can choose a name together. And Alfie I chose for her because she was very much Monster Girl, 'cos she thought Monster Girl was actually with the monsters. And she believed that she was a monster and because of the things that had happened to her. She is basically me as a child. I really thought I was a monster when I was little. I saw monsters and I believed I was one. And she still carries that as a voice or as an aspect of me and....

- You saw them in the present at that time?

58.54: (C:41:1) Yeah I saw them in the mirror, so I saw me. My first vision that I remember - and I have patchy, patchy memories - but I remember this one distinctly 'cos I was at my mate's house and I was looking in the mirror and I saw this horrible monster looking back at me and I looked round (laughs) and my friends didn't react

funnily. And I think I kind of figured that was me, and that I was the monster and underneath it all I was a monster. And certainly from therapy, what's come up loads is the idea that I just feel that inside I'm just a squishy black mess of badness and that if anyone really sees what's inside me, that's it. They'll get bad, or someone will hurt them or they'll just reject me or hurt me and I deserve it.

39.38: (C:42:1) And then you give someone like that a label and no wonder I ran to that label and believed I was schizophrenic because it was like – “Yeah, I am wrong, there is something really bad underneath the surface that no one else can see”. And yeah, that was it really. And that did so much damage, it's taken me a long time - even before therapy - to kind of start to undo that. And I kind of undid a bit of that pre-therapy and now in therapy I'm actually starting to understand why I had to try and undo that 'cos it's like, I've still got that now.

40.08: (C:43:1) And that's really hard. Having a relationship with a therapist - a therapeutic relationship with a therapist - when you believe that underneath all of this, once they see past the nice person, they'll just see all this yuk that came from your childhood that will be really bad for them, they won't be able to cope with it. Not surprising it's taken me a year to even get there really. And it'll probably take another couple of years to be honest I think before I feel able to share some stuff or even go into some stuff with her. But yeah, so I think labelling is dangerous. And medicating is dangerous.

- Do you remember the circumstances that first brought the label up?

41.00: (C:44:1) Yeah. I think I really hid all the stuff in my childhood, so no one knew. I had like when I was 14, 15, sort of teenage, I believed that I had an alien inside me and that alien was gonna do bad, make me do bad things, or it was going to be bad in some way. I still wouldn't talk to people about it and I kept it all in. So I self-harmed and I kind of did all these things in secret and it was only when I went to university, had the breakdown, and kind of, it was a 'no means weak' way, like, “Take control of your body! You can say no!” And I think I saw a poster saying that you could say no and obviously I hadn't been able to, and I'd had a lot of other traumas, not just the early childhood stuff, but throughout the whole childhood teenage (experiences), like layer upon layer. And that just triggered it. I started to get flashbacks. I started to get, hear 3 horrible voices, and get very paranoid again, (and to) believe the alien conspiracy theories, and it all just disintegrated.

- And the voices hadn't been there before then?

42.00: (C:45:1) No, that's the thing, I hadn't... well I don't know if they hadn't been there to be honest - it was the first time I *realised* that I heard voices. I always thought it was people talking about me and so I may have heard voices pre that, I think I just had visions and unusual beliefs which aren't really unusual contextually. But I don't think, I don't remember hearing them anyway. But yeah, I started to, it was when I was at someone's house and I heard people talking about me and I thought it was them and they were asleep and I got quite freaked out with that. I was studying psychology and philosophy, so yeah, I didn't really, I don't know whether I kind of felt, “Oh no I'm going crazy”, or yeah, I don't know it just was, it was really, really confusing and, but I didn't tell anyone again.

42.47: (C:46:1) It was only when, after dropping out of university and- I told people about the rape I had in my teenage years, because that was, I was suffering with depression, I felt crap, I was traumatised. And I was struggling to wash and look after myself and I was self-harming a lot, so I needed to drop out, so I gave people that reason. Almost like (incomprehensible) this is why I'm struggling, and I kept everything else hidden. And, and then I think it got really obvious to people, my parents, that they came to visit me and I hadn't been looking after myself, I hadn't been eating the parcels they sent me, I was neglecting myself. So the psychologist who was working with me around anxiety and depression, because that's all I told them about, knew that something more, they would have to section me if I didn't go back home and go and see a psychiatrist back home.

- So this was a psychologist at university?

43.40: (C:47:1) Yeah, clinical psychologist and yeah she was, I was meant to be on an anxiety disorder programme and, yeah, it was obvious that something wasn't right I think and she knew I wasn't taking care, so she was like you know, "Going to have to section you self neglect if you don't go and see someone". I was on sort of meds for depression as well that were making me quite zoned out. And yeah...

- What sort of medication was that?

44.05: (C:48:1) Antidepressants and sort of anti-anxiety, so I think I had some Valium and Lorazepam-type stuff, but old style antidepressants, like Miltipaxin, which is quite sedating. Seroxat which made me dizzy, so I tried a few, few different things. I didn't really like them. I hated the feeling of being chemically altered. It generally made me quite paranoid. And I don't like feeling my senses are dulled, 'cos it doesn't feel safe then. So that generally triggers more things for me.

44.39: (C:49:1) Yeah, I went back and saw a psychiatrist down in my home town and they were, they'd actually, it was the first time I'd told them about being poisoned and followed and all this other stuff. And the voices and everything and they were really nice. They actually said, "It's ok, we know what's wrong with you, we see this a lot in people who go to university, you know, it's ok. Come into hospital, we'll just start you on some medication and get you back out there", kind of thing so it was like, "Oh" (*relieved*)... That felt like the nicest thing someone could say to me. It's like, "Wow, someone understands. It is me, I'm *ill*, but you know, someone can make me better."

45.23: (C:50:1) I wasn't diagnosed straight away. I was in hospital for about eight months, but I was actually fighting for a diagnosis 'cos I knew what it was by that point 'cos I'd been around people. I knew about schizophrenia 'cos I'd been in hospital for a while and I knew that stuff that I was going through was similar to other people with that, but I just wanted someone to actually say the word.

- They were holding back from giving you the diagnosis?

45.48: (C:51:1) Yeah, that's it, it kind of I was on the cusp of the new first episode psychosis and, they'd already given me the diagnosis actually, they were holding back

from *telling* me about the diagnosis because an OT who I had a good relationship with, said to me, “You know, you don’t want the diagnosis, don’t ask.”

- This was a professional or service user?

46.06: (C:52:1) Yeah, an occupational therapist who I got on really well with, she’s just like, “You know, you don’t want to think about that. And I was like, “Why if it’s an illness I need to know about it so I can deal with it. And she’s like, “No you don’t go down that route”, of course I didn’t push it but they gave me the schizophrenia diagnosis anyway and I was discharged with schizophrenia and re-admitted with schizophrenia, discharged with schizophrenia and...

- What was the treatment at that point?

46.37: (C:53:1) Medication. Completely, I went through lots of different anti psychotic – or neuroleptics - you should call them really.

- Do you remember which one?

46.44: (C:54:1) Yeah started on Olanzapine. Massive weight gain, I put on like about five stone - more than five stone - in eight months, well, yeah, in the first admission. That seemed to work really well, but then I was still paranoid underneath it ‘cos I still believed in the conspiracy but I didn’t know that I wasn’t meant to *not* believe it. No one had told me really what recovery was, so they were like are you feeling better? “Well yeah, the voices are less and this is better, but I still believe in the aliens”. And then was released and thought I was being followed, got really panicky, told someone at the day centre and then got re-admitted again. Changed my medication to Risperidone I think, then started lactating which I thought was evidence of the aliens because I was like getting breast milk and no one had told me it was a side effect and it took a nurse to recognise that – it’s quite obvious if someone’s lactating - and then I had pads and everything, which was really humiliating and they changed it to Sulpiride, and then Sulpiride worked a bit. I was discharged, readmitted again and, but there was another- I think yeah, can’t remember what it was, there was another reason why I couldn’t take Sulpiride. Tried me on Haloperidol, I had ocular crisis, which everyone thought was anxiety, and gave me more Haloperidol to deal with that (laughs). So I ended up in A & E with my eyes rolling back and not being able to breathe. That was again very freaky.

48.09: (C:55:1) And it’s just eventually it was Quetiapine was the one I settled on and that was the one that suited me quite well actually. I had sedation, I had, occasionally would get shaky, obviously the weight gain - I’d gained a lot anyway - got diabetes from the Olanzapine probably, certainly got diabetes on my first admission, and there was all these side effects, but actually it felt like, “Well why worry about them?” If you’d asked me what side effects I had, “I’d have said oh it’s alright, it’s just I’m a bit tired in the morning.” I wouldn’t have told you about, ‘cos I thought, “Well that’s the treatment for my illness. What else is there?” And actually that didn’t seem as bad as the horrible things that happened when I was experiencing in the psychosis, so you know, it didn’t seem important really. But yeah looking back now I had loads of side effects.

48.58: (C:56:1) And the suppression of emotions, which is a way, if I'd have gone for therapy while I was on medication, I'd have got some stuff out of it - and I did - 'cos I did look into myself and that, but the thing that's helped me go deeper is my emotions, the emotional reactions I have to things 'cos I can talk about them and work out where they are. I've got more voices than I've ever had because of those reactions I think.

- But then you had also said that you had been very wary of talking about what was going on, on an emotional level, in case that triggered another set of diagnoses.

49.30: (C:57:1) Yes, with psychiatrists. The good thing about therapists is they're not about to diagnose you. Especially a therapist you pay for. "She's working for me!" This is how I remind myself. Yeah, that's it. Emotions were something I feared within psychiatry and they were discouraged.

- How could they be separated?

49.53: (C:58:1) Diagnoses and that's the thing... You learn. It's like, "I'm here to talk about your beliefs, your delusions, your voices. And it's ok you can feel distressed in relation to those, but if you start to feel like too emotional or too reactive or whatever, then that's like, that's not about the biological, that's something different. So I think on one of my first or second sectionings, they got a specialist in to see me and said I had schizophrenia and borderline personality disorder because I did definitely have those things, but also there was this emotional element that was around - the trauma - and that's personality disorder. And being labelled with that was really horrible. People stop listening to you, they stop believing the things you say and what you feel. And it's like it was so horrible.

- Because of the personality disorder element.

50.46: (C:59:1) Yeah, like you're being manipulative. Or if you have a difficulty with a nurse it's about you being, you supposedly having a great relationship with them and now you're turning on them or something. And I've never turned on *any* nurse, but like there was one nurse who was just really horrible to me. And because I had the label personality disorder she (*the nurse*) said (to) the psychiatrist, (that) we had a great relationship. He (*psychiatrist*) thought I was reacting to her. Whereas she had actually said some *really* horrible things about me and other patients and she was really nasty. But like your emotional reactions are questioned and it's just like... I don't know how they can separate, 'cos I think it's one and the same: voices and emotions are massively linked. But, yeah, they don't know what to do with them.

- And presumably the implication is you're the ill person and the other person is there to treat you, that they can't be part of that equation.

51.39: (C:60:1) Yeah. That's really, yeah, kind of a, it's a funny thing I suppose 'cos I think that's where a personality disorder comes from. If somebody feels like a weird emotional reaction to you, because they're picking up on something, that means you've got personality disorder, if it's something they can't put their finger on that means it's personality disorder. It doesn't mean that they've got some issues that

you're triggering for them, it's all about individuating the person and ... Yeah, like my psychiatrist at the moment, who I'm hopefully - I really wanna disengage with psychiatry at some point, hopefully without the schizophrenic label, but even with it, I've had enough now - I asked her, I just asked her, "Have you got any experience in sort of like treating people with dissociative issues like myself? And she said "I'm not gonna share my CV with you". And I was like "No, I'm not asking to see your CV". She said, "I'm not justifying myself to you". I said, "I know I just wanted to know, 'cos I know you have the schizophrenia stuff, but I wondered if you'd come across this and whether, I wanna know if I can talk to you about it." And she was like... and she refused to discuss it with me and felt very challenged and also... And I was at pains to be reasonable at that point and she also said after that I had BPD. And I said, "No I don't have BPD 'cos I know the symptoms and I don't exhibit those symptoms." I've trained myself not to! (laughs). That sounds really horrible, but I know that I don't, and, not enough to be diagnosed anyway. And she was like, "Well I think you do." And I was like, "Well can we discuss it, it'd be really good to hear which bits you see in me." And she was like, "No there'd be no point. I'm not discussing it." And it was all about me pushing her or being difficult, but nothing about the fact that she felt challenged by me. And ...

- Something about challenging or a perceived challenge to someone's experience or position. That in bringing up those questions it would question her professionalism?

53.54: (C:61:1) Yeah and, it was a challenge, she believes very much in psychiatry and this biological model and I think me - even me not being on medication, I know that she finds that very challenging. And so sometimes she'll sort of not plead with me, but very emotional, "Are you ready to go back on the meds now, (Participant C)?" You know. And she's like, What else can we do for you? You're struggling, you've got voices, you know, please, you know, what, you won't accept out help, why won't you accept our help?" And I'm like, "I'll accept your help, I'm just not accepting the medication, 'cos I don't think that's helpful for me, but I'll do other things, you know if you give me a CPN or something to talk to, that would be fantastic. She's like, "No this is the treatment and you're not having a treatment for your illness." Really frustrating.

- When did you stop taking medication?

54.38: (C:62:1) Two and a half years ago now. Really hard. Had really intense sort of experiences for the sort of like withdrawal of that.

- What medication did you stop taking?

54.48: (C:63:1) I stopped like 3, 4 years ago I stopped my antidepressants very slowly 'cos I needed, I was on antidepressants, antipsychotics and mood stabilisers. So Quetiapine, and Venlafaxine and Carbamazepine. (I was) on maximum doses of all of them as well, so like really high dose. And I need to be able to get up in the morning, so I stopped the antidepressant, 'cos I figured I could probably deal with the depression if it started, so I managed that.

- And which one was that?

55.16: (C:64:1) That was the Venlafaxine, the antidepressant. And I got off that, that was cool. And nothing terrible happened - I was struggling a bit while I was getting off of it, but I found other ways to cope with the way I was feeling. And really believed that I needed the other two, one to help me sleep, but to manage the voices and to manage these experiences that I was still really frightened of. And then, (I) started to play around with the dose really, to function and to do work and if I had an early meeting I knew I couldn't take it like that morning, so instead I'd wake myself up at like 4 or something and take a dose early and I, or I'd take less or I wouldn't take it that day or I'd take just a little bit. And I started to just mess around with it and then after a few years of messing around with it I realised I was actually taking very little regularly and started to worry about the effects on my brain, I started to worry... You know like the Joanna Montcrief stuff... And just knowing from other people that had come off and thought, "Well maybe, maybe this is actually something I could do." But I had a lot of coping strategies by then and came off over the course of quite a long time, like a year I think.

56.26: (C:65:1) Came off, partly off the mood stabilisers, so I was only taking one tablet, rather than about three or something, and then the antipsychotic I was taking a bit more and then I started to come, bring that one down, and eventually came off the anti-psychotic and still took mood stabilisers for about a month or two to help me get to sleep 'cos I didn't know how to fall asleep without chemicals. I'd never done that before and I was just laying in bed next to J*** (*husband*) going, "So how do you do this?" You know? I was just like was unconscious I didn't know the process, and that was really frustrating, I used to just like lie there going, "Come on. Sleep, sleep, sleep!"

57.05: (C:66:1) But eventually it worked, you know. I learned Tai Chi, I kind of started to make my brain chill out a bit more and it was do-able but I had like major, I did still have like, I believed that people were interfering with my brain. It was actually psychiatry (that) prompted that one. 'Cos they, they realised I was off (*the medication*), I told the psychiatrist, they panicked - it was a newby psychiatrist, like a baby doctor - HSO - who was doing it. Initially me and J*** went and we told her that I'd withdrew a month ago and it was ok, it was very difficult but I was managing and I explained why and I took some research with me to explain that this makes sense and I was very, we had like a strategy meeting first. And I spent a lot of energy dealing with psychiatry and less energy dealing with myself I think sometimes. And it was fine until the end and then she panicked and went, (sharp intake of breath), have you ever acted on the voices? Have you had trouble with the police?" And just as we were walking out of the thing - in front of everyone else - she was asking me these really panicked questions and it was like she'd just remembered "risk assessment!" And then I got a call to come in for a formal risk assessment and the psychiatrist was stressed and she got in trouble with the psychiatrist, and they all wanted me back on the meds straight away, and....

- So everybody's anxious.

58.11: (C:67:1) They were really, *really* anxious it was like we were trying to calm them down. But that made me bad 'cos then the voices were yelling at me and I was having this thing where she was telling me I was more likely to kill people and kill myself and that this illness wouldn't go away, just 'cos I wasn't taking medication.

- What were the voices yelling at that point?

58.26: (C:68:1) (laughs) They were yelling that it was right, that I was ill, that I was crazy, stupid. But then there was the other voices as well, it's almost like- 'cos there were those that I could distinguish, but it's almost like chaos where everyone's yelling at once and you can pick out bits of it, but it just got so loud that I felt that I couldn't even hear the person that was telling me all these things, 'cos it was just, I just got stressed and I think the (more) stressed I get, the more stressed my internal world gets. And without J***'s support I would have gone back on the meds, it just felt too much at that point.

59.00: (C:69:1) But yeah then because of that I think I started to think that people were doing brain surgery (on me). When I was on the tube and I got really, couldn't go to work because I felt that I could feel people in my head, experimenting on me and all that stuff and of course, in retrospect, *that was psychiatry*, that was the doctors. They were, they were trying to do stuff and I felt very powerless and then that set off my beliefs again, which then reinforced their idea that I needed the medication. Whereas I did know, once I- J*** knows. Luckily J*** holds onto the fact that this was a response to it, that I'd lost, I was in a daze, I wasn't able to function, that's the worst I've been for a long time. But he held onto the fact that this was understandable and helped me get through it. This was before therapy. That's why I had the therapist actually, I realised that I needed someone to talk to.

- You've talked a lot about these experiences in relation to trauma and something that was happening at a much earlier age. Is that something that you're able to talk about?

01.00.07: (C:70:1) In terms of the kind of trauma or the link?... Not so much. Yeah, I've always, there are certain traumas that I feel comfortable, I can tell, I can say that I was raped as a teenager, I can say that I was abused by a vicar when I was like 7, and part of a lot of people in my community were abused. The family-related stuff I find much harder 'cos I'm still... It's like I know that my mum was abused by people and that she was really traumatised. The idea that she might not have protected me from those people is quite frightening. And I'm still struggling with it, so yeah, you talk around it. What I can say is that the challenge with all that is like, some of my voices, especially my younger voices, have things that come out that I don't remember. And that's really confusing, because I'm more of an analytical person. So I'll be trying to look at the meanings and what is that voice trying to express? And I won't take it literally. Don't wanna take it literally. But my therapist is more of a mind that, yeah, "There can be symbolic stuff, but also a kid doesn't... Like there's things that I remember feeling and going through my childhood and also just the things that happened in my family that don't make lots of sense when you look at it and it's really the circumstantial evidence of bad things happening is huge, yet I'm really denial. And I know sensibly that yeah, "Stuff happened." And bits of me - my voices know that, but I don't wanna know that. God, so confusing, and I think it might be a while before I want to know that. So I talk about it in terms of dreams. I just, yeah I de-thingy it. Sort of distance it a little bit.

01.02.00: (C:71:1) But I do think though once I've dealt with whatever it is and it's, again, I still feel there's probably an element of symbolism in there as well. I don't

take everything literally. But once I've worked that out, I imagine that the Not Yets won't be there, or at least they will, I won't need them. I might still have some of them and some of the, the kind of, yeah some of my experiences. I guess I've got a capacity and I translate everything around me into symbols and into voices or beliefs so you know, this is my creativity I guess, and my survival strategy. But I won't need it to survive those horrible things from my past, because there won't be an issue. This is my hope anyway. And I think without therapy I really wouldn't have the opportunity to do that, so I'd be forever completely subjugated by these experiences. I wouldn't be working and I wouldn't be having a relationship like I do. And I wouldn't, yeah, I wouldn't be here really. I think I might, might not have survived if I hadn't have had the opportunity. Not even just like the therapy now 'cos it's more recent, but just someone therapeutic, someone to actually to see the sense, even support workers. Network for Change, they were - and the Hearing Voices Group - they were like huge 'cos they were the first people that really said, "There's a meaning here, there's something, this isn't just an illness randomly grabbing you and dragging you like a demon into hospital where other people make you better. There's something here". And I think other people seeing that before you're ready to see it is so key.

01.03.35: (C:72:1) And I needed that stuff to feel ready for this therapy. 'Cos imagine getting me to this kind of therapy like 8 years ago. God, I would have thought the therapist was nuts. The first time that someone mentioned that the voice might be representative of an abuser - my abuser – I was really angry at them. So I wasn't ready for it. Still not entirely ready for it.

- And presumably, that would feel like a really frightening notion.

01.04.00: (C:73:1) Yeah, definitely. I think the way I get around that isn't the abuser's in me, or anything like that, 'cos I think that feels horrible. But I think the abuse, the powerlessness, that's got the voice and that voice remembers what people have told me.

- The experience.

01.04.18: (C:74:1) Yeah, and that's the way I can get around it without feeling that I'm carrying round these abusers, abusive things. And I think that's ok... Yeah it's challenging, but I suppose I'm conscious of time.... Yeah, properly Horrible.

- Shall I pause it now?

01.04.42: (C:75:1) Yeah.

Participant C – Interview Part 2

- So (*Participant C*), we were just saying that following on from the previous interview that the starting point of the second interview would be talking in a bit more detail about the process of the therapy that you've been through and where that first started.

0:26: (C:76:1) Cool. There's probably some bits of therapy I might not have told you about - I can't remember which ones I've sort of talked about because I think, I've been in counselling a lot of different times during my life. Like at university I saw a counsellor and that was because I was self-harming and struggling and the GP kind of encouraged me to go and see someone. They got a bit freaked out, because although I didn't tell them about the voices and my beliefs they knew that something wasn't quite right, so I saw them maybe four times before they said I think you really need to see a psychiatrist. So that was quite short-lived.

- And you weren't able to speak about the voices and some of your beliefs.

1:10: (C:77:1) No, not at all, so....

- Why not do you think?

1:13: (C:78:1) I don't know, I think I just, I'd been so used to keeping secrets for my whole life, that the idea of talking to someone about it just seemed really alien. It never occurred to me, it wasn't like I was going, "I really want to tell them but I'm scared to", it's just yeah, it just seemed strange that I would even mention it so the only thing I could talk about was the self-harm and the feelings of anxiety and sort of my mood 'cos they were the sort of acceptable things you could talk about as a student. But I think other people around me know, knew that something was a little more off than that.

- Was there something that a therapist could have done at that point that would have helped you to have talked about all of those things, or was that too early for you?

2:07: (C:79:1) I don't know, it's hard to say in retrospect. I think there were little things I can remember her doing that, that kind of perhaps made it harder for me to settle. I think 1) we didn't see each other enough, because obviously as soon as she realised it was something she felt she wasn't able to deal with, she then got rid of me, which was probably because she just couldn't, it just felt like she wasn't sure what to do. So that wasn't good. Because obviously there's no chance to build up a relationship. I think maybe keeping seeing me would have been a good thing.

2:42: (C:80:1) But also I think she was, she, I think she found the way that I responded to the traumas. I told her a bit about some of the traumas that I'd been through and she found it strange that I talked in a very, almost like matter of fact and/or jokey way about them. Not jokey like making giant jokes, but I think I talked about them either quite matter of factly, or with a lightness and a kind of a smile, and I think she found that a bit disturbing 'cos she'd say it just didn't feel congruent and I could get what she means 'cos I've witnessed people doing that but it's just, yeah, they were my first attempts to communicate some of the stuff that had happened to me and I guess I didn't feel particularly, that it was... that she understood. And I think before I build a relationship with a therapist, it takes me a long time to really feel there's some trust there, so I take spend a long time sussing it out. And those kind of things are blocks for me. I need to feel that people really get why I would speak in that way about stuff, so I think I expect quite a lot from my therapists. And she might have been able to do it, if we'd seen each other over a longer period of time, but just not

enough. And also I think I had a whole lifetime of not telling anybody, so it would have taken quite a long time to get the point where telling someone was ok.

4:15: (C:81:1) Other thing though, she could have asked - thinking about it, 'cos actually it was only a couple of years later when I told the psychiatrist about it and the only reason I told him was 'cos he asked the question and I don't think anyone had ever asked about voices or beliefs or unusual things that had happened to me. It just hadn't come up 'cos everyone assumed it was depression. So maybe if she'd have asked I might have said something. Mmmm I hadn't thought about that, yeah simple things.

4:41: (C:82:1) So after her I had a little bit of CBT, 'cos a psychiatrist put me to an anxiety management CBT thing.

- This was after you had received a diagnosis of (*schizophrenia*)-

4:53: (C:83:1) These were all before. So initially this psychiatrist was treating me for anxiety and depression 'cos I hadn't told him. This was up in S***** when I was still a student, so he referred me to an anxiety management programme that I couldn't actually attend 'cos I was too anxious! So then I had individual CBT with a psychologist, and again I had maybe 2 sessions before she realised something was not quite right. And I wasn't eating or kind of washing at that stage, so that's when she mentioned about potentially sectioning if I didn't sort of get help and speak to and sort of ...

- Get help. Wasn't she providing help?

5:34: (C:84:1) Yeah, I think it was 'cos, I don't remember the exact context of it 'cos I think I was quite confused back then, but I think it was something like she thought I needed to be in hospital and if I didn't sort of, yeah, it's a really strange context, 'cos of course I was seeing her so I was engaging, but if I didn't sort of do that she was getting to the point of considering recommending that I get sectioned 'cos of self neglect because I wasn't looking after myself. I could never imagine having that conversation with a psychologist 'cos they don't section you, I didn't know that at the time, but I think she'd picked up that something wasn't quite right and was trying to get me to say whatever it was. As it was it kind of freaked me out and I think I told my parents that I wasn't coping and they came and moved me back to L*****, which is where I saw a psychiatrist and they actually asked the question about the unusual experiences and I told them – not everything, but I blurted out quite a lot and that's when I got the diagnosis.

- What led them to ask that question in the first place?

06:42: (C:85:1) I think I was probably looking very confused and sort of – yeah, I think I was probably looking really distracted and quite distressed and I was struggling. Because at that point I had really sort of intense beliefs about aliens and being followed and I was seeing things and hearing things and it was all very, very intense. But I was also quite disconnected so I'd struggle to kind of look at people and kind of, my parents wondered, when they came to pick me I do remember just kind of wondering round in circles and just finding it really hard to understand what was

going on around me and kind of just feeling – yeah almost like in a dream. So my behaviour had changed enough for people to start questioning what was going on.

7:37: (C:86:1) And it might have just been actually the psychiatrist ‘cos they always cover the basics and I was an 18, 19 year old girl who is, like dropped out of university and looks a bit weird, it's quite a standard psychi question to go, “Hmm have you ever had any of these things?” Because they'd be querying if I was having an episode of psychosis. Yeah, so could be the context, so probably a bit of me looking a bit weirder and a bit of them, me fitting their box because it's quite common for young people to kind of go through that.

8:12: (C:87:1) I think going into the medical sort of system and getting the diagnosis eventually through that, that sort of halted the therapy, so I'd have little bits of counselling, but then there was no counselling or therapy while I was an inpatient or - even when I was sort of discharged, I was discharged to a CHMT, so I had a nurse who tried to do a bit of CBT for psychosis for me but out of a book! And yeah, it didn't make any sense to me at all. It just felt like why are you working through a book with me that's full of really cheesy ideas that don't relate to me at all, and you're giving me homework. It just, it didn't feel helpful, it felt very box - tick box approach to it.

- What were the cheesy questions?

9:02: (C:88:1) I can't really remember, so it's more of an impression than a definite – again it was a long time ago. But it was those kind of examples - someone says something and you then, yeah, you have the thought and then the feeling and then the voice or whatever and just trying to and again you think, “What else could they have meant by that?” And it was a very kind of – ok you had to give an example, so I had to try and think from the week before what example have I had when I've had a strong reaction and my voices have got worse and relate something, so I'd usually give a false example ‘cos I couldn't think of anything. So it's almost like we were working from a false starting point which was my fault ‘cos I should have just said I can't think of anything but I think I felt that I had to produce a concrete thing that we could work through. And then we'd work through it by – yeah, what were you feeling, what were you thinking, what else could they have meant and yet it was coming from a completely disjointed place because it wasn't a real example and my examples wouldn't have fitted into that but there was no talking around it or kind of exploring what it meant to me – it was a conveyor belt, it just felt really prescribed.

- So in trying to fit in with the therapist's need to deliver a therapy, you ended up with something that seemed to be quite far removed from the truth.

10:35: (C:89:1) Yeah definitely, and I think the other thing was ‘cos she was a CPN and didn't know – like many of the CPNs who haven't been trained in CBT for psychosis - she didn't appear to be very confident in what she was doing. So yeah, I guess I didn't have much trust that she knew what she was doing either - but it wasn't in that nice way of the peer support movement where you're both kind of finding your way together, and it feels like you're moving together towards something – hopefully. It was more, “I don't really know what I'm doing here, I'm a bit nervous, I've got a

book, I'm going to hold to this book and make sure we don't deviate from the book and you're going to fit into the book and it'll all be fine.”

- Why is that different from working with someone in a peer support relationship?

11:28: (C:90:1) I think... mmmmm, it is that difference- and it's not necessarily peer support, 'cos peer support can be done prescribed like that, and it can be, so maybe it's not actually the difference between peer support and sort of bad CBT. I think it's whether you feel that the person understands the whole of you or is trying to understand the whole of you and whether you feel seen, and that you're kind of – I think the idea, or my idea is that whether it's any kind of therapy, including just the peer support version of support, is that you as the person are sort of setting the direction and the other one's acting as a guide. They might not know the territory that well, and they might not know where you're going, but they're kind of giving you a bit of trust to direct it, and they've just got some skills and tools and understanding that can help you, but it's not, it's about you and where you're going, not about them and their comfort zone. Although that does influence it so it's not as clear cut,. But yeah I think the feeling of being seen and having – that it's relevant to what you're living. 'Cos if it's just a tick box and just a kind of a work that you're going through that doesn't relate to where you're at, it's not that helpful.

- Maybe there's also something about the therapist setting themselves up in the position of the one who's going to lead, which if they're not confident in their ability to do that, once you've already created that precedent, and you put somebody else in the position of being the person who's going to follow or have something done to them, then maybe that's an element to it as well?

13:23: (C:91:1) Yeah I think so - again it's like if you go into the jungle and the person who is leading you into the jungle has like a kind of bluffer's guide to the jungle book and he's going, “Right this is a tree”. That's not going to give you lots of faith in their ability to help you through this.

13:40: (C:92:1) I think also just, it's a common thing for me - certainly in my early days of therapy - is to try and please the therapist and the whole me feeling that I needed to actually produce an example and work through it the way they wanted to, didn't help. I know in a lot of my therapy that's been a theme for me where I've felt I needed to do what they wanted of me. It's only recently I've been able to say, “No this is my therapy here, if I'm not happy with this I can kind of go in a different direction and say it.” It's taken me a long time to even mention unhappy things to therapists, I've been a very compliant – probably a pleasure to treat. The problem is that every therapist probably I imagine has the sense they've never really got to the bottom of what's going on with me, because I do everything they say and I'm quite jovial and I will talk about the deep stuff, but still that final bit of connection doesn't happen and I don't really move. Until recently, so...

- Do you feel the therapists that you're mentioning in that context were able to see you were doing that?

14:48: (C:93:1) I think, I think she probably had this un-named, weird feeling, 'cos it was shortly after that that I ended up diagnosed with BPD for a while - borderline personality disorder - not because of her, I was an inpatient again, they again had this feeling that something wasn't quite right and couldn't quite understand what it was. So I went for about 6 – 8 months diagnosed with BPD before I got the schizophrenia thing back again, and once I got labelled with that during the course of my work with her, she changed dramatically, 'cos - again my perception of this is that it gave her a word for the un-named feeling that she had and then she could put me in a box and say, "This is personality difficulties coming out here, this is why I feel uncomfortable and why we're not getting very far with it." And then it changed so she was talking much more about my relationship with my family and my mum and making what I felt were quite a lot of judgements about me, but she seemed a lot more comfortable than when I got relabelled – yeah, I can't even remember what she was like then.

- If her approach was to work with CBT, perhaps there wasn't a facility to name that feeling. With another mode of working – for instance, psychoanalytically - one might call it a transference, or one might be able to name that thing and then be able to work with it.

16:25: (C:94:1) Or even tell someone about it, yeah I think - again its all guesswork but if you've got, if you're a nurse in a CMHT and you've got an unusual feeling about a client, what do you do with that? You could tell your supervisor but then your supervisor might or might not be understanding about that and you might also feel de-skilled. I'm sure I provoked a lot of de-skilly feelings in people back in those days. So, yeah, it's just not set up for working and I think no one really recognised how complex my issues were back then. I think if they knew what my issues were it would be quite obvious that I needed someone that had that kind of support and could name those un-named feelings and work them through themselves. But looking back it was obvious that that just wasn't going to work for me, those kind of very superficial approaches, it wasn't really going to get me far.

17:21: (C:95:1) Also that CBT gave me a few tricks, not that therapist, well that nurse, but the actual CBT therapist I saw for the anxiety in S*****, even though I saw her a few times, the one thing that I've carried with me from her - I think you pick up little bits from lots of people - was just the traps of thinking. She gave me just a hand out of ten traps that you could fall into and I recognised a lot of them and it didn't- it wasn't like a hallelujah moment, but throughout the rest of my life I've often thought about catastrophising and the different things we can get into. I've not thought about it in a pure CBT way, but I've kind of looked at a lot of my ways of thinking about situations and tried to think of differences and why I do that. Yeah, it gave me - that little thing was useful and feeling that she cared as well, 'cos I think she did care. So not all bad.

- Being in a therapeutic relationship with someone who was interested in you, who cared about you sounded important.

18: 30: (C:96:1) Yeah I think so, 'cos at that time I didn't care about myself and I didn't feel – I think I probably felt that there was so much about myself I was hiding I felt a bit fake. Because I wasn't telling people about my past, I wasn't really telling people about my voices, I didn't feel I really existed and I had all these aliens and

everything and it was just like all my interactions with people just – yeah, it wasn't me and my whole inner world was so chaotic anyway that to have someone actually try to understand, even if they don't understand, that was quite important. It's therapeutic in itself, without anyone trying to delve in there, so mmmm, it was good.

19:20: (C:97:1) As I say the kind of therapy stuff stopped quite a lot until I went to college - oh I had lots of assessments, I went to a therapeutic community, I don't know if I mentioned that last time.

- I don't think you did. Just to clarify, that particular therapy relationship, the CPN delivering CBT came to an end and there was a gap.

19:52: (C:98:1) Yeah, that was more like she was my CPN and she just occasionally did little bits of CBT so it wasn't even sort of a programme, yeah. At some point I dropped out of the system and at some time I stopped having a CPN and I've got no idea how or why. It was all mixed up because I was still diagnosed with personality disorder when I stopped seeing her I think (interacts with cat). It's really chronologically wonky for this. Let me think, I was initially diagnosed with schizophrenia initially when I saw her and then we started doing that and it was seen as BPD and at some point I stopped seeing her, I think I was an inpatient again. And during the inpatient admission, they decided to get me to a therapeutic community which was more 'suited to my needs', apparently. And I was there for a month and stopped being there 'cos I ended up back on the ward 'cos I had quite a severe suicide attempt and it was just, it wasn't the right place for me, and then was discharged.

- What was the experience of that month?

21:16: (C:99:1) Oh that was hell. That was like being in a Big Brother House, full of very traumatised people. And having - there was no sense of individuality, you couldn't have a one to one conversation with a staff member, everything had to be done in group and if you felt in a crisis, you had to wake everybody up and have a crisis meeting, which - because I struggled with people, I didn't like groups particularly, that was very hard for me. It felt very behavioural, like, "Don't have a crisis otherwise you'll have to get everyone up." And it was really hard, because I was seen as having BPD, although I was on loads of medication still, because they still – they changed my diagnosis from schizophrenia to BPD, but I don't know if they really believed it because they left me on all the anti psychotics and all the mood stabilisers and stuff, so that was quite weird but I was the only person on all of that medication in the centre, but also they believed that I wasn't paranoid and I wasn't hearing voices, and that I was just taking on an illness identity. Which was hard because the more I was in that situation, the more paranoid I was feeling and it was worse because the other clients or people, residents, felt that I was different as well so I got quite, things got really, things just got really intense for me and I ended being sort of separate from everybody and no one would come near me really, because they all thought I was going to die. I know it sounds really intense but yeah they were actually convinced that I was going to successfully kill myself and they didn't want to be part of that.

23:15 (C:100:1) And I think hearing other peoples' traumas - some people had gone through such horrible things – it was like incredibly overwhelming, because I can kind of relate to a lot of people and I think I don't have the outer skin, I used to not

have the outer skin there, and so I'd carry so much of other peoples' traumas, so it's like flooding really. And the staff just didn't handle it particularly well. So it was, it was really uncontainable and really unsafe.

- How did they not handle it well?

23:57: (C:101:1) I don't think they handled it, I think that's it. There was an absence. I think it was obvious there were problems and I was feeling quite unsafe and that people weren't, yeah, that I was starting to get quite separate from people, and that you know some of them actually believed I was hearing voices and the doctor and all of that believed that things were getting worse for me I think 'cos I was in such a triggering environment it was getting worse, but they didn't do anything because their thing was about you didn't have individual time you had group time, they didn't really challenge it in groups. It was just left to a point where I'd taken, took a few sort of, I took an overdose and refused treatment which was the first time I'd ever taken an overdose and refused treatment because I'm always so polite. If people find out I've done something I don't want to make it bad for them 'cos I don't want them to have to suffer because of me, so I would always accept treatment even if I didn't really want it. It's the only time another, the one person I knew who was still sort of semi speaking to me, or not completely separate from me, recognised the sort of signs of having overdosed, 'cos you can tell it in people 'cos they generally feel a bit happier and feel a bit perky. She kind of recognised that and told staff, and I admitted I had, but yeah I also said I didn't want, I said "I'll go to the hospital if you want 'cos I know it's not fair to be here, but I'm not going to accept treatment this time. I've just given up."

25:29: (C:102:1) And yeah, that sort of thing happened and yeah, I also ended up walking in the middle of the road at night. I just went out and just thought that's it. It was all, it was all really intense, but they just didn't know what to do with me I think. And because they weren't set up to believe that I could be experiencing sort of so-called psychosis, they didn't know what to do with that part of my experience. I mean I was obviously traumatised and I did have difficulties with my personality and the way that - complex trauma stuff - so I fitted the criteria in so many ways, but there was this other stuff that they didn't know what to do with so they ignored it and I never really got to talk to anyone about it and it just put me in a really unsafe position.

- So it defined how you had to be looked at and related to? And the parts that didn't fit the picture couldn't be taken into account.

26:32: (C:103:1) No and again I think that whatever it is that I provoked in people – that sort of de-skilling - and also some people thinking that something wasn't quite right again, so I think I split the team quite a lot. Not intentionally but I think some people thought there were things that needed to be addressed that weren't, and some people didn't so there was just a lot of feelings around me. And you'd think in a therapeutic community this would be the perfect place for those feelings to be explored and dealt with, but instead it felt very judgmental and very... when things were taken to groups and explored, it was almost like 'bad you'. It felt really punishing.

- Why was that the case in that particular therapeutic community?

27:21: (C:104:1) Yeah - that's the thing, 'cos I've known there to be other therapeutic communities and it's one with a really good reputation. Having said that it's now closed or closing or at least doesn't do overnight things, overnight treatment anymore. And there was a suicide, one of the girls I knew there, she broke her back, she jumped out of a window. And that was someone who was just so young, yeah, the atmosphere didn't feel very safe. But why?... I don't know, I mean that's the thing, I don't know. I think perhaps they were so focused on that particular approach of everything being group, that there was no room for the individual and it was almost like there was an ideology of this is the way it's done, this is the way the therapeutic community works and this is the beauty of it, that there was no room to look and reflect and go, "could we move the model slightly, and could we be flexible here sometimes", they just felt a lack of flexibility and a lack of reflection about their part in the power and their part in it. But because they thought they were doing that and they thought they were reflecting on in it they didn't reflect, it's almost like the model itself they thought had reflection inbuilt and they really weren't thinking about - I don't think they were thinking about - what was wrong with me in the place. I don't think they really noticed it until quite a bit after and I think they did notice it eventually and that's why it's changed a lot now.

29:02: (C:105:1) But it is funny that of all the places I've been, that should have probably been the one that was actually quite useful, 'cos it was at least my trauma, 'cos my trauma had been ignored until I got the BPD diagnosis. When I got the BPD diagnosis suddenly everything was all about the trauma and about my emotions, and I was actually initially quite happy that they were actually looking at that, 'cos I knew there was loads of stuff that was being missed from the schizophrenia part, but ...

- Because with the schizophrenia diagnosis those parts would be considered less important, less relevant?

29:37: (C:106:1) Yeah, so it's like, "Let's get the schizophrenia under control and then everything will be better". So it's a very medical, sort of simplistic way and it's almost like they can't see the extent that the trauma's affected me, they couldn't... that all my self harm and all my kind of post traumatic stuff was seen as like part of the schizophrenia. And then they switched their glasses and saw the BPD and the trauma part and then couldn't see the schizophrenia part, but I thought while they're looking at the trauma part, perhaps someone will help me, 'cos I knew that things weren't quite right for me, I just had this – I knew that things were very intense inside and there was a lot about how I felt about myself and other people that wasn't quite helpful. I was like, "Yes! Finally get some therapy then", and I didn't.

- What was the next encounter with therapy?

30:30: (C:107:1) That was an assessment, because after going back to the ward, 'cos again they transferred me back after the most extreme time and I was still seen as BPD, but just about when I was ready for discharge they got me to a psychotherapy assessment with an actual psychotherapist this time, at a clinic that tends to deal with people with personality disorders, but also deals with a bit more than that. And had a really cool therapy assessment with a guy and I actually really liked him, I thought he really got me – that's the first time, 'cos like I said before, the big thing with me I felt that people didn't quite understand or see, but he seemed to. It went very deep for an

assessment, and I told him some of the things about the alien that I believed was inside me and also about some - not everything about my childhood - but some of the sort of like later abuse that I'd been through. And he picked up this really cool thing, he picked up on - and again it's the only bit that stayed with me through the assessment - but I described the person who abused me as kind of like cold and sort of a bit alien, and he just made the link between that and my alien and wondered whether there was a link. I said no, but maybe, and then I thought about that quite a lot after the assessment and I kind of, yeah he did it in such a way that it was ok to think about, whereas other people that had maybe suggested that the alien was a metaphor for the abuser - 'cos it obviously is really - well I think it's a metaphor for the abuse, but yeah, other people had done it in such a way that felt like, felt much more challenging, as if this is what it is and I naturally resisted that. Whereas he did it in a way that was just wondering if there was a link, rather than "I wonder if the alien is your abuser?" It just felt helpful.

32:36: (C:108:1) But unfortunately, while I hoped that I would have therapy with him, he did believe I had psychosis and he believed that the beliefs and everything were genuine, which meant a lot to me - and the voices and stuff - but he also rejected me for therapy because of my 'poor ego integration', which I didn't realise why until I got a letter about, well a few years later, one of those sort of referral letters where they refer you to another service, and it said that in the summary and I felt really kind of cheated actually 'cos I was like, what do you mean by poor ego integration? I still don't know what he means by that. But yeah I guess for whatever reason I was too vulnerable for therapy, or he thought I was too vulnerable for therapy. But I think if they had have given me therapy back then I'd have had a quicker journey, because I was ready for it. I think the fact that I was able to listen to him and kind of actually think maybe he's got a point at least to me suggests that I could have made use of it. But yeah - that was my last therapy encounter before - apart from a bit of grief counselling at sort of university, at college, tiny little things - then the next sort of therapist I saw was when I came off meds and got into therapy.

- So how long ago was that assessment that you were just talking about, where you felt you could have been ready at that point?

34:01 (C:109:1) I think it was about 2000ish. Start of....

- So 12 years ago.

34:10: (C:110:1) (Laughs) God that's a long time. It's actually really frustrating and I'm sort of smiling and stuff but I'm like, it's so obvious! Everyone who's worked with me has known that there's stuff going on that they've not quite got a handle on, even the therapists. And I do feel that it was a giant flashing thing that there was more to it than schizophrenia or BPD, and everyone had some kind of weird feeling, but no one actually was willing to look into it. I don't know whether it's that kind of, it was, it just felt unsafe and it felt like something big and horrible was lurking there so let's just pretend it doesn't exist 'cos it was just too much.

- And the outcome of that assessment was he was saying that he didn't feel you were ready for psychotherapy at all?

34:57: (C:111:1) I don't know, 'cos I was actually thinking about it, it was while I was at the end of an inpatient admission, so I never really got to know the outcome except that I wasn't accepted for therapy. It was only like 5 years later when I saw the letter that said about the ego integration thing, but it was seen as I'm not ready for therapy at all, so it wasn't like not yet. There was - suddenly the therapy dropped off the agenda. I kind of dropped out of services, I kind of took, I realised that I wasn't gonna get any help through the psychiatric system and it was making me worse, not because they wanted to, but just because I was continually not getting any needs met, it was like just reinforcing everything, so I got into Hearing Voices Group and Network for Change and sort of the voluntary sector and got some stable support and then once I had the stable support all of the kind of re-triggering stopped and my difficulties with people, my self harm sort of reduced and I stopped self harming completely myself, by using a self help book, and I got a handle on myself again. I stopped expecting them to make it better for me. And then, once I'd got stable I got myself re-assessed because I wanted to get rid of the BPD label, 'cos it did fit me for a time, but it didn't fit me for a person. It wasn't the whole thing and I no longer met the criteria and they went through quite a lengthy assessment with a person that was a sort of senior psychiatrist to my psychiatrist. My psychiatrist refused to see me as anything other than BPD, he just, yeah, he just wouldn't.

36:34: (C:112:1) And yeah, went through the assessment and then spoke to lots of people, like my family and other people that have treated me, and they decided I was either schizophrenic or schizoaffective, but certainly not BPD, just with sort of post trauma stuff. Which is a complete joke 'cos it's just labels, but those labels were a lot easier to bear than BPD I think. And I had to change my psychiatrist 'cos he refused to agree with it. He was just like "No, this is all crap." So I got a new psychiatrist, and again they were then treating me medically as if it's a biological illness again which is easier. I didn't believe it, by that point I think by I'd learnt enough that all these labels are stupid but yeah it was a lot, I felt, if I had the choice between either being seen as a personality disorder or as someone who is ill, I prefer the ill, 'cos at least people listen to me. Whereas with personality disorder I think they'd stopped listening.

37:35: (C:113:1) But it did mean I had to squish down, to kind of keep that diagnosis, to make sure I didn't get labelled with BPD again, it meant I never talked to any professional around my feelings or the trauma. I just kept that in a box and, yeah, said the right things. So I'd focus, I didn't lie to them, but when they asked me how I was I'd focus on the things that were related to the things they were willing to see, or I thought they were willing to see and just didn't mention my emotions and dis-association and stuff, 'cos that was, that would just get me re-labelled and I didn't want to be re-labelled.

- So you had to match your experiences to how you felt people wanted to see you.

38:19: (C:114:1) Yeah, that's it, and that's really crap. Because it's not like I did that consciously but I've realised how much I've done that, certainly with the psychiatrist that I've got -well I haven't seen her for ages - but the one I've currently got, I started to try and talk about the trauma and the feelings once I was in therapy and tell her a bit about how that was going in therapy and she labelled me BPD temporarily. She didn't change the schizophrenia/schizoaffective (diagnosis), that's still there, but she

kind of said, she said BPD. And I queried it the next time and she said well, "It's, with the trauma you've been through it's impossible to think that you wouldn't have borderline personality disorder. It's ok, it's not a judgement, it's just that you've obviously got that." And I found that really disrespectful because I was like, yeah, that's crap. It's, yeah, I've been traumatised and it's affected me but saying that you have to have BPD if you've had that extent of trauma is just disrespectful.

39:27: (C:115:1) So yeah, I hadn't realised til starting to try and talk about these emotions and experiences with a psychiatrist, how much I have made a choice not to talk about it and I then understood why I hadn't talked about it 'cos yeah, exactly what I worried about came back. This sort of, the box approach which I've sort of hated for the whole time of it.

- Sorry, just to rewind, the previous assessment you were talking about. What kind of therapist did that?

40:01: (C:116:1) I don't know, I'm thinking he would probably have been psychodynamic 'cos I think the centre was heavily psychodynamic, but yeah I can't remember exactly.

- So there was this second assessment now that... quite a long time later.

40:19: (C:117:1) Yeah. And that was me really so I, I contacted the B**** Centre after coming off meds and after realising that some of this stuff was still really active for me, that there were still some real issues that I hadn't dealt with...

- Could we talk a little bit more about the decision to come off medication, and what that experience was like, before we come onto the B**** Centre?

40:49: (C:118:1) That makes sense. It was complicated – I'd previously believed that the meds were keeping me 'well' 'cos I'd believed I was ill and I always thought I'd need meds for life, and I'd been told I'd need meds for life and then I think I got this job, the voices manager job thing, and I knew that there was no way on all the medication I was on that I could function in the mornings getting to work. So I started to reduce some of my dosages, or take it slightly differently and I started to actually mess around with it a bit more.

- How were you feeling in the mornings? What made it so difficult?

41:35: (C:119:1) Oh yeah, I was sedated. If you'd have asked me were the side effects of my meds I would have said actually there's no side effects, they're fine, 'cos I'd lived like that for so long. But I would not be able to wake up properly, so J***, who I was going out with at the time would wake me up, bring me coffee, I'd fall asleep holding the coffee in bed I'd kind of fall asleep, and then he'd take the coffee away and then he'd try and get me breakfast, so bring me some Weetabix or something and then wake me up again and I'd try and eat Weetabix and then have to go back to sleep and then he'd wake me up again and *again*, and eventually I'd be able to get out of bed and it was just – yeah, really hard.

42:14: (C:120:1) And that was through the first few years of working. So whilst - and that was with me reducing some of my dosages, so I think prior to reducing a little bit I was probably just zonked for most of the morning.

- This was anti psychotic medication?

42:30: (C:121:1) Anti psychotic, mood stabilisers and anti depressants. So the first thing I sort of did was reduce the antidepressant 'cos I figured I could probably cope, I'd know if I was getting depressed again and I felt low on medication, (and) off medication so I wasn't sure if it was really doing much. So I reduced that just really slowly and nothing major happened really. I did go through periods of being low and the psychiatrist wanted me back on it, but I was also quite clear that I didn't want to do that, then...

(Person enters the room and leaves, pausing the interview)

43:29: (C:122:1) Cool. So yeah that was the antidepressant, so once I'd got off the antidepressant, I was still really sedated, but I still believed I needed the other stuff,. So what I used to do was if I had an early meeting I'd just take a tablet less at night or just sort of mess around with my dose a little bit, still believing I needed it. And it was kind of weird, I didn't think I was coming off the medication, just using it a bit more intelligently and going up and down on the dose, and it didn't really affect things. And over the course of maybe a year, I'd reduced the dose quite dramatically so I was taking a lot less than I had previously and coping. I was having sort of increased experiences, but I was coping with them.

44:13: (C:123:1) And then, what happened? All that time I wasn't having a decision to come off or anything, I was just trying to work and have a life and a few things happened. I got married, went to B*** and didn't take any medication while I was in B*** at all, because it was so relaxing. I wanted to be able to experience it directly, I was aware now that this was putting a block between me and the world. I just wanted to have my honeymoon. And I was so relaxed in B*** and the pace of life was so nice, that actually I didn't have this giant like psychotic break or anything, I was just quite calm. I did have experiences, but I felt able to deal with them.

44:54: (C:124:1) Went back on meds, a low dose, when I came back 'cos I realised being in London isn't like being in Bali and I was under a lot of stress, so I knew I needed it but it kind of got me from the idea that I needed meds, that meds was like essential to my wellbeing. And then I read a Joanna Moncrieff article which was about brain shrinkage, and because I have a very vivid imagination, I could actually feel my brain shrinking. I knew it wasn't, but it was almost like it really highlighted the damage these meds might be doing to me and I'd been on them quite a long time.

45:25: (C:125:1) And then I remember sitting on the sofa with J*** - all within a very short space of time - and just feeling so disconnected from him and just like there was a big gulf between us and it wasn't as if we'd had an argument or anything, I just didn't feel fully present and so all of those things together I just thought I need to get off them now. I've got to make this decision and yeah made a plan.

45:48: (C:126:1) Got off the anti psychotics, sort of slowly reduced them, still kept on the mood stabilisers so I could sleep and then came off the mood stabilisers. It was quite frightening. I was still a bit unsure as to whether it was a good idea or not and I did go through a really bad period about a month after being off the meds when I was trying to tell the doctor that I'd gone off the meds - and was handling it very adultly, trying to coax them through it, give them a bit of support 'cos they were a bit freaked out -and I started to believe that my thoughts were leaking out of my head and there were people doing brain surgery on me and I was still trying to work at this time as well, so trying to get on the tube with people like having all my thoughts felt very violating. And yeah, I had to stop working 'cos I just couldn't go out and I also find it very hard just to make decisions, I found it hard to stay present, J*** felt as if he'd lost me, as if I wasn't there. And this is probably how my parents felt when I was initially struggling, it was like I didn't, the (*participant's name*) that he knew was no longer in the room and I just, yeah it was a weird time.

47:03: (C:127:1) But luckily J*** kind of stayed strong to it and - I tried to get help from the system again, but they were like, "Take the meds or don't, you're not going to get anything else from us, so it's like if you don't take the meds we're not going to help you, there's no other option, there's no therapy or anything". So yeah, we got through it. And a lot of it was just hanging on in there and trying to get, yeah just trying to sort of wait it out and know that this is part of it. And got some coping strategies, like listening to music so that people would only steal the music from my head which got me back into work so I believed I was sharing Deftones with the whole the tube carriage and trying to strengthen my mind so people couldn't do kind of brain surgery on me, got me back to work and when I was back at work I felt more in control and then I was more sort of centred, but it was a real hard period.

- How long did that last for?

48:00: (C:128:1) I don't know. It felt like forever. Time didn't really make any sense in that, in that period, but I think it was probably, I was only off work for maybe 2, 3 weeks. I think those kind of experiences lasted longer, maybe a couple of months, but they were most intense for that sort of 2, 3 week period.

- How long ago was this?

48: 25: (C:129:1) This was - I've been off meds now for 3 years now, so this was probably 3 years ago. And work were really supportive which is good. And then, the voices, yeah it was around that time that the voices really came back as well and I really self harmed for the first time. So all of this stuff was kind of coming back and I'd mostly not had voices while I was on the meds, I'd had some but they weren't present all the time and then they came back and it was like, yeah, I just felt unable to cope and thought, "Damn it I need therapy!" And hence my next lot of assessments and seeking out the B**** Centre. Once I realised the system wasn't going to offer me what I needed, they weren't going to offer me therapy. They did offer me CBT for psychosis and I've studied CBT for psychosis and I know the tricks and there's no point in me going into CBT therapy really – it's not gonna teach me anything.

- Why was that all that was on offer?

49:29: (C:130:1) Because that's the latest thing for psychosis, so NICE guidelines say you offer CBT for psychosis 'cos it's effective and, yeah, evidence-based treatments. I think psychotherapy isn't yet evidence based, so it doesn't enter their heads at least in that particular team. They've got certain paths that they put you on and, yeah, the psychotherapy really isn't for someone of my diagnosis.

- So you sought out something different.

49:59: (C:131:1) Hmmm. Yeah. I, what did I do – I'd spoken to Jackie, Jackie Dillon (Chair of Hearing Voices, England), and knew that she was involved with the B**** Centre (*psychoanalytic therapy provider*) and I spoke about needing to go into therapy, so she suggested I speak to them. I also knew they were cool with the post trauma stuff and the voices, 'cos most, I did sort of email a few therapists and few of them were a little kind of like, "Ooooh I don't know if we quite do that," 'cos I was quite honest about the fact that it was because of the voices that I wanted therapy. And I wanted to check that they could deal with that, rather than get into a therapeutic relationship and realising 6 weeks down the line that there was something about my experiences that just freaked them out. So I was being quite sensible.

50:40: (C:132:1) I went to the B**** Centre and - the problem I have I think with that particular assessment I had, was I seem really good. I seem very sorted, I seem very reflective, I seem like I could engage really well in therapy and they saw that, but what they didn't see was all the other stuff that I don't show. And of course they can't see that, but the person that did the assessment didn't look beyond the surface, so they placed me with quite an inexperienced therapist who spent a year - I mean we had nice chats - but we didn't get anywhere. And I think I probably said last time is the time that we actually, that she'd noticed and took it to supervision and I think that we weren't really, there was no threads in the sessions and we weren't working through anything, we were just treading water.

- Was she afraid of something?

51:29: (C:133:1) I don't know, I think she just didn't notice that we weren't moving initially. It's like, 'cos it seems like we were getting somewhere 'cos I was talking about some stuff that had happened and, you know, I quite liked her. But, yeah, I think it just passed her by that we hadn't moved and, and I knew that we weren't moving because things like my relationship with J*** had got a bit - my physical relationship with J*** had completely gone sort of six months into that therapy. I think it was because things were coming but I wasn't working through them so I just... sex and all those kind of things just was not on the agenda for me and I had quite a lot of like, some new voices came up and I had quite a lot of feelings of not being able to move and things happening to me and so I was getting quite flashbacky, but yeah, I wasn't really doing anything with that and maybe I didn't feel safe to, I don't know.

52:29: (C:134:1) And yeah, she brought it back and said we'd been in therapy for ages and she didn't feel we'd really gone anywhere, and I kind of agreed with her and said ok, I've gotta really focus on this and try and keep a thread and so we had about two sessions where I was really trying hard and I didn't feel safe, 'cos I think I disassociated in the sessions and I also split off from her 'cos I think there was a

time I took a photo of my family that I'd found that had been posted on Facebook and it provoked a massive reaction in me - my voices, but also my perception of self. And I was seeing myself as a monster again and it was, it just had a massive reaction. I didn't realise that the photo was an old photo until J*** mentioned it to me. I thought it was just happening and he said, "Well, you saw that photo earlier today and do you think there might be a link?" And I was like, "Yeah actually that makes sense. So I took the photo with me to therapy, wanting to really explore it and we didn't. It didn't go anywhere. I wanted her to ask me and we did, and I kept trying, and I felt she just didn't wanna go there or couldn't go there and I think that's, yeah, I just disappeared at that point and I think the few times I disassociated with her, she didn't know what to do with it and so she was sort of, I got the feeling that she was a bit unsure how to handle things and I kind of went, and I didn't feel safe, I lost my sort of - I lost trust in her I think.

- When you say you disassociated. How did you experience that?

54:08: (C:135:1) Yeah, it was weird as hell, it kind of felt, there's, there's a few different experiences I had. One was just stepping back so that physically it felt like I was a long way away, and I couldn't hear her. It's weird, it really affected my senses and, almost like I was watching something else somewhere else and she was there, but, and I think that was when I tried to discuss the photo 'cos I think I probably felt that she wasn't going there or something and I just sort of, yeah, I actually switched off from her, but physically, so it's almost as if yeah, she was a long way away.

54:51: (C:136:1) But, there was other things around, again, everything in the room getting giant, as if you're a tiny little thing, like a little child and again going really far back and kind of just hearing myself and, yeah, and I guess what a therapist would say regressing or something. But yeah, it's a really weird sensation of... And I used to have that quite a lot anyway, but never in therapy and, like I used to have it so that I'd be walking around and it felt like the world had suddenly got bigger or I was, yeah, things changed quite a lot and there was lots of things that were happening in my life of kind of, just, yeah, just feeling very disjointed and having gaps and things and just the way it's always been. And it was the first time that that had come into therapy and it was really freaky to have someone witness some of that. I can't say exactly what it was like 'cos it's not, I can't see it happening from her perspective, but whatever it was must have felt quite weird, 'cos we didn't really talk about it as well. She said that there was some regression but we didn't talk about how that felt for me, or her or anything like that.

56:16: (C:137:1) And I think it was me that made the decision to terminate therapy and get someone else. I wrote her a lovely email saying how, yeah, it was really good and thank you and you've helped me see what some of the issues are for me now, I need to move forwards somewhere else. So it was a Dear John letter really and I was very careful to protect her feelings 'cos I also knew she wasn't properly qualified, she'd only just qualified at the end of our therapy. But yeah there was loads in the therapy that was really difficult, like she'd just repeat what I was saying sort of the echoing thing without the, it didn't feel very validating 'cos she'd just repeat the end of the sentence. And all of those little things plus that just made me feel very, just you don't know what you're doing. Yeah got an assessment, got diagnosed with disassociative disorder.....

- Where was this?

57:14: (C:138:1) This was P*****, so I actually paid for a private assessment. I didn't, wasn't actually planning on doing that, I was just trying to seek a therapist that was ok with that kind of disassociative stuff and wouldn't freak out of me and also was ok with the voices. And I think they're quite rare therapists because I've noticed over the years therapists who do have that area of - not everyone, but the ones I've seen - can get a bit freaked out when something's not fitting into that.

- What sort of approaches at, you said, P*****?

57:48: (C:139:1) P***** – well they were recommended to me 'cos they were a specialist disassociative clinic. They work with the NHS, but also do assessments and they can recommend therapists that they've worked with. And it's, yeah I don't know, I imagine there's gonna be a bit of psychodynamic in there, 'cos there always is, but I'm not sure, I don't think it's purist. But yeah I ended up, they gave me the SDQ Somatoform Disassociation questionnaire as well as the DES, the Disassociative Experiences scale, and I filled those in and I actually scored massively highly, especially on the Somatoform one. And no one had ever asked me those questions, all these weird body experiences I'd had, I always thought I was like freaky. When I was a kid I thought I was maybe severely ill and I would just spend my whole life and no one ever spoke about them, just like no one ever spoke about my voices and then I got, I can talk about my voices 'cos I've got a language. All this body stuff I couldn't speak about and then on this questionnaire they were asking me about it and it was the weirdest experience. (Noise off) That's just the alarm. I shall be quick then, yeah, can't have a think about therapy and then miss therapy, that would be really bad! There's a weird avoidance thing there.

59:12: (C:140:1) But yeah, it was really cool. I ended up going for the assessment 'cos I did wanna find out... I don't know. I kind of wanted to talk to someone that understood that stuff and I was also thinking... I wanted to get rid of the schizophrenia label I think also. I think it had done its job and it was like it stopped everyone from seeing me and I was thinking, well, "The assessment will be with a psychiatrist and a psychotherapist and it will be to try and untangle how much is post trauma and disassociation, how much is psychosis. I actually don't believe either of them are good bubbles 'cos they're not real. But I was happy to play into this sort of idea that they are real with the hope that someone would look at it and go actually this all makes sense given what you've gone through. The schizophrenia doesn't make sense, but the post-trauma stuff does. And they did that. They assessed me, they said that, whilst I did have obviously periods of psychosis, that it was understandable based on sort of the trauma and, yeah, came out as DD/DID, depending on how it goes.

1:00:30: (C:141:1) Took that to a psychiatrist, psychiatrist was like, "Yeah we knew you were diassociative anyway, but you know, you're still schizophrenic and we're going to treat that" (laughs). So that didn't do anything. I was hoping they'd like get me trauma therapy or something, but no. So I found a specialist dissociative therapist....

- Privately?

1:00:47: (C:142:1) Privately yeah, again recommendations from people and I knew someone else she was treating. She was quite well respected. That went completely pear-shaped. I was seeing her for over a year and she was, when I last met you (*for interview part 1*), she was the one I was seeing and it was helpful to see her, I think it was very helpful to focus on the disassociation and actually get some communications with my voices and my different aspects and I've uncovered some of the things that had happened to me from different perspectives 'cos the different bits of me have different perspectives on it. And that's been quite interesting, but it's also been harrowing as hell. It was like having your soul ripped out weekly, or twice weekly and it was too intense.

- What was it in the therapy that made that...?

1:01:44: (C:143:1) I think the reliving stuff. The whole, the whole thing that... yeah, it went, for me it was going too quickly because I was still getting my head around the idea that there's different parts of me that have different ideas, 'cos I've seen them as voices for so long it's like seeing them as aspects (of me) is quite challenging for me even though it makes sense to me, but... And then the more you delve in the more it actually increased the times that I wasn't present in my body, and then to feel that there were things happening, even though there have been things happening when I've not been aware in the past, but to have that really brought into focus, it was really hard. And then to have to come back in a session and see something that a child has drawn and it's really horrible and then to leave with those feelings and not to have had a chance to really think, "How do I feel about this?" It just felt really unsafe.

- When you say a child had drawn...

1:02:43: (C:144:1) Yeah, it kind of like, yeah like Blue, (*incomprehensible*) one of my voices-slash-aspects, yeah they hold bits that I don't hold. So it's ... yeah, and so that they would sometimes draw something – of a traumatic situation that maybe I'm not ready to think about or it's just sort of kept sort of in a box, I don't quite know how it works.

- You mean literally draw something?

1:03:13: (C:145:1) Yeah like literally not there, which is freaky as hell. And it's more freaky for me to have a therapist witness that 'cos I've known that there has been that sort of stuff going on for quite a long time, but, and if you look at some of my notebooks and things from where I was sort of properly crazy, it's, yeah this isn't like a new thing. But to have someone witnessing felt really vulnerable and also to actually look at some of the things that they've drawn and think what does that actually mean, rather than just dismissing it as crazy stuff is really hard. And the therapist was also a very strong personality and I felt she pushed a lot and had ideas about what this meant that I don't want to think about yet, and I'm not ready to look at what this actually is. I don't even know if it's real, I want to work my way around it, I don't want someone else telling me that this is real and to deal with that, I wanna feel that I'm making sense of it myself.

1:04:15: (C:146:1) Yeah and I didn't feel so, 'cos she was quite inconsistent about things, like just in favouring some of my voices-slash-aspects over the others and

almost, “Why aren't you trusting me yet?” That kind of almost desperation she seemed to be feeling. And it just started to, yeah I didn't feel safe again. And so yet again I found another therapist. There was a time I think she missed an appointment with me and I was just waiting outside her kind of place she sees me in the rain feeling completely like lost and, and confused and again some of the younger voices were really freaking out and, all of that and I was doing the kind of adult, it's ok there's probably a reason but I was really worried she'd been killed or, there was a proper abandonment thing going on that I've never experienced, 'cos I've never trusted a therapist enough to feel abandoned by them. So I really had kind of gone quite deep with this one.

1:05:10: (C:147:1) And then she got angry with me on the phone 'cos she thought that we were seeing each other later on that day and, yeah, she felt that I was... She was being quite nice as well but she did start to get frustrated and sounded quite angry at me and raised her voice a little 'cos I think she thought I was trying to avoid the therapy by telling her it was the time when it wasn't and I actually think that she got the time wrong, but she couldn't see that and she couldn't see how frightened and scared some of my bits were, some of my aspects and parts of me. And instead of having someone who could reassure, (like) “And it's ok”, it was more kind of a punitive and, yeah, I ended promptly. I decided that moment I was gonna stop therapy with her, but I did see her for a final session which is something I've never done. I will always walk away from a therapist, but not do a final session. Cos there's no point 'cos I will just cut off. But 'cos I knew that I'd started to attach to her I was like, “You should stop this properly.”

1:06:10: (C:148:1) And I found myself an art therapist. And I looked really carefully at the websites and all the stuff and checked her out and she works with dissociative clients, so she gets the whole disassociation part, but she's also not a purist, she's not kind of a fanatical disassociation person. She's more about helping you process stuff in time. She works with kids as well as adults and I quite like that because it means that she's really sensible in how she handles my younger voices and really careful about her language, 'cos the other therapists - although she said she was understanding of that, there was quite a few things, she said one of my aspects was annoying, or irritating. She didn't mean that, but she'd said it and they'd heard it and I'd heard it and it was, yeah, little things like that hierarchies develop so then she's much more... Even when I do that kind of thing she brings me up on it and I think that's good. It's much more about processing and not re-traumatising. I think the other therapy re-traumatised me a bit, unintentionally. And I feel a bit safer. She's kind of a bit more across from me, she's quite down to earth, she's got a piercing and she's got ADHD, which I quite like because she's quite fidgety, which stops her being the calm therapist with the tilty head. So I feel, by her being slightly chaotic, but also being really good at recall at what I've said previously, and quite respectful.

1:07:39: (C:149:1) And yeah, I've only been seeing her sort of, about, I think it's about 8 times now, so I don't know yet. Don't know if I trust her, don't know if I, I think the whole idea of going to so many different therapists has made me really cautious about therapy. But I feel that she's actually being quite practical. Like last week some of my voices were kind of feeling quite murderous towards my cats – that sounds really bad (laughs). But yeah, I know it's 'cos of the vulnerability, especially 'cos of the little kitten you've got there, and I was triggered by – I had to go to the doctor and have a

kind of a personal examination that brought back quite a lot of bad stuff, and so last weekend urges to sort of really hurt the cats were huge and the voices were huge and I took that to her and we looked at it. She didn't make – what the other therapists would have done is made me go into the why and what the voices were remembering and what it was, but she didn't which I thought was really good 'cos I was scared about mentioning it in case we went back into it 'cos I'm not ready at the moment.

1:08:38: (C:150:1) And so what we did is to talk about why that might be and we talked about vulnerability and how maybe it's that kind of projection thing, but also the idea that we need - 'cos I'm quite a rational person, I think a lot about things and make sense of them, but don't necessarily express them, so we talked about ways of expressing that anger. Hence the punch bag that I've got and the stripey socks. Because I've noticed, the whole reason my body got into a bad state is because I don't drink or eat sometimes I find it very hard to sort of know what my body needs, and I got massively dehydrated, so it's about helping some of my voices and my aspects feel really hating towards my body because it got broken because of the knee (*which was damaged recently*), and there's a lot of body disconnection going so it's a way of helping me feel more connected and help my little ones feel more connected, hence the socks. Because one of my little ones chose the socks and the idea is they can look at them and go, "This is the body, this is my body", not... "This is the body we've gotta keep healthy."

1:09:37: (C:151:1) And it's just little things like that that the other therapist would never have done because she was going through a model and hers was, "It's an attachment thing, you need to attach to me." It was all about her, attach to her and also I'm not there for practical strategies, I'm there for the trauma stuff.

- You felt that was explicitly said?

1:09:5: (C:152:1) Yeah, it was kind of, yeah it was. Because I used to, I was saying, 'cos I'd read like the treatment guide for disassociation that the ISSD do and the first stage is meant to be safety and I would say "I don't feel safe yet, I need some safety strategies 'cos I've done a lot of self harming and like doing all this crazy stuff, I know that things aren't stable and I wanna be stable before we go into the trauma". And she was like, "I'm just being led by you and you're giving me this stuff", but also she was saying, yeah "Get the strategies, but you can do that yourself, this is, you know, when we're here, this is what we're doing, we'll do what the little ones want". And my little ones did want to talk to someone about things. Yeah, it was explicit, whereas this one seems to be very mindful of helping me get some stability first.

- When you say the little ones needing to talk about something, is this them mediated through you, or are they able to speak more directly?

1:10:56: (C:153:1) Bit of both. Sometimes through me - and I would prefer it to be through me personally (laughs) - but there are times, there are times when they'll communicate without me or without my conscious me and that's happened with J*** sometimes, like if I'm particularly triggered by something on, like on TV, there are some triggers that I respond to by feeling, yeah, flinching and kind of being very freaked out, which I'm there for. So even though it feels like it's not me, it is me. But there's also ones which produce like, almost like re-enactments or something, where I

feel like I leave the building and don't actually know what's happening. And that's ... weird really because it means that other people around me are holding bits. Like the bits J***'s witnessed, he's seen me as a traumatised child in inverted commas in the shape of his wife like, I don't know, battling off kind of people and things and just really, yeah, being freaked. And he holds that, but I don't because I just hold his memory of holding that. And that's just weird as hell.

1:12:08: (C:154:1) And that's why I want art therapy because partly I've got so many conflicted feelings about this. I wanna explore it and I think sometimes just exploring it from different angles in an arty form helps me work out what I feel about it and integrate it 'cos I don't want it to be split forever. I figure these are my memories and these are my experiences, and I just wanna get to the point where I feel safe enough to bring them back into me, rather than have them as separate.... Weird.

- We're probably going to have to finish quite soon. I'm thinking if this had been available to you from the beginning, when something was starting to go wrong for you, when it was starting to come to the surface, would that have helped then?

1:13:06: (C:155:1) Yeah, I think if people weren't so busy thinking I was schizophrenic or borderline and sort of looking at the boxes, they would have recognised that this disassociative stuff has been there all along, and I was actually much more visibly disassociative when I was in the hospital, thinking back to how I acted and stuff and what people told me about how I was, I had quite a lot of periods where I just wasn't me. And if they were willing to look at that they would have noticed, but they weren't able to see it and if they'd have given me the right kind of support perhaps I wouldn't have spent so long going in the wrong direction. So yeah, I think it would have helped, but that's the thing, it's almost like the box itself of being schizophrenic stops people from thinking and the box of being borderline stops people from thinking and, even the box of being disassociative can stop people from thinking I think.

1:13:55: (C:156:1) I will never call myself, I won't say I've got DID or anything like that, because I think that's just another box. I always say I'm disassociative and I'm a survivor, that's as boxy as I'll get 'cos that's an accurate description at the moment. Yeah, I just wish they'd get rid of the boxes, because diagnoses are meant to help you get the right treatment, but what they seem to have done for me, at least, is help me get the wrong treatment and prevented me from getting the support that I needed. Which is really damning I think. And it does make me feel angry, I'm smiling while I say it 'cos it's my trademark, you know, but actually I do feel quite angry 'cos there's a lot of suffering that could have perhaps been changed. Having said that though if I hadn't have gone on this journey though I wouldn't be me and I feel a lot and have grown a lot through it so, you know, I wouldn't rewind time and then get into therapy sort of like 15 years ago and then not go through this 'cos there's no point. I am me and I'd be someone else.

- I guess I'm also wondering if you had been less resourceful and less determined, where things might have ended up.

1:15:16: (C:157:1) Like the people I work with in prison, and/or, secure units or long-term facilities because yeah, there's so much... Even telling part of this story, you kind of realise that things were so stuck and people were starting to see me as a long-term severely, never-gonna-get-better - I've got notes upstairs actually about, when I was going through the assessment I had to go through my old medical notes to send them so they could look at the history, so it's not just my word, it's kind of what's written, and there's this one, a sort of discharge CPA thing that was saying I need long-term sort of residential care and they were gonna look for that. And it's pure luck that I met the Hearing Voices Group and it's pure luck that I met Network for Change, met Ron Coleman (*high profile figure in the Hearing Voices Network*) at a thing and Network for Change happened to be there and I happened to speak to them. That's the first time I thought of living independently and it was pure luck then that all these other things happened and it's, I don't think it's about me being massively resourceful, I was really resistant to this for the first couple of years, this was when everyone else was doing it, running around me going, "Look there's another way!" And I was like, "No I'm ill!" But somehow something changed in me through them believing it could change and then I got resourceful. But like if I hadn't had the luck to meet those people, then I would probably have never got resourceful 'cos I'd never have known there was a problem, it's like it's so stuck the whole system, it's very hard to see alternatives when you're in the middle of it, and reliant on those around you seeing it first. Yeah, it's not a mental health system, I think that's the

- What is it?

1:16:59: (C:158:1) I don't know, but it's nothing about health... It's social control really. Yeah. Dumping ground. I think it's really sad for those really good people that work in it because it's not that it's full of evil people that try and hurt them and I think if they heard the story that I've just told you, they would probably feel really bad because they're trying so hard to make things better, but they're operating in the wrong system, so...

- How could it be done better?

1:17:35: (C:159:1) Do you want the realistic version or the idealised version?

- Both.

1:17:42: (C:160:1) Ok, I'll do the idealised, and the idealised is get a new diagnosis because diagnosis clouds everything really. Talk about issues that people are having at the time and try and see people holistically. I hate that that's the idealised version because actually that's really human and that should be the realistic version. I mean, to add some more ideas, I think have sort of sanctuaries where people can actually feel safe. I think the therapeutic community and hospital environments were just really re-traumatising and, and made everything that much worse.

1:18:10: (C:161:1) And I think prioritising the person's narrative and understanding that that's going to change as they grow. So if you interview me in two years' time you'll probably hear a different take on what my issues are. Cos it's you know, I'm changing and it's alright, we should actually encourage people to change and grow and be flexible in the way they see themselves. Whereas, the system at the moment

acts very rigid and encourages you to have a fixed view of yourself and not change, “You are schizophrenic. You are this.” So, yeah.

1:18:39: (C:162:1) I could add lots of things in where people with lived experience could walk along side you, and all of those beautiful things, I think that's very necessary. And also completely ditch the whole lines approach to the mental health service, taking away where you have a diagnosis that indicates a certain treatment, you've got NICE guidelines for it. And part of the NICE guidelines thing – it's a pile of crap, but probably don't write that in your thing (laughs) - but yeah, this whole conveyor belt approach is just flawed, so having a more holistic approach and looking outside of medical treatment...

1:19:16: (C:163:1) Realistically what I think can be done - because I don't think we can get rid of diagnoses, I really want us to but I don't think we will, not for a long time. I think work is individually listening, really, really listening and also reflecting themselves. I think, I created so much conflict and confusion in the people around me, not intentionally but because there was all these different parts of myself trying to be heard, and my identity was confused. That people had very strong feelings about me, but even therapists and even people that were meant to reflect on it didn't. Even my last therapist, who's supposedly the best therapist in the universe - not quite, but she's a respected, famous therapist - found that hard to see her part in it. It was all about me and, yeah, I think, if we get more human about this, perhaps it's easier for therapists and workers to think about their part and actually be honest about – mmmmmmmmm. So I think just honesty and yeah flexibility. I think it's not a big asset actually to try and not pigeon hole people and let them change and encourage them to be flexible in their thinking. But I think maybe the workers have to be flexible first. So maybe encourage workers' flexibility and thinking about people and then they will then encourage that in the client.

1.20.44: (C:164:1) So yeah, I don't want much really (laughs).

- Just thinking about the time and maybe we should finish there.

1.20.56: (C:165:1) Yeah, did you manage to get all your questions 'cos I know you had quite a list?

1.21.03: (C:166:1) Cool.

INTERVIEW ENDS

Example of meaning units - Participant C

- through therapy understood
~~Appreciates~~ that same trauma may be
- 01.02.00: (C:71:1) But I do think though once I've dealt with whatever it is and it's, again, I still feel there's probably an element of symbolism in there as well. I don't take everything literally. But once I've worked that out, I imagine that the Not Yets won't be there, or at least they will, I won't need them. I might still have some of them and some of the, the kind of, yeah some of my experiences. I guess I've got a capacity and I translate everything around me into symbols and into voices or beliefs so you know, this is my creativity I guess, and my survival strategy. But I won't need it to survive those horrible things from my past, because there won't be an issue. This is my hope anyway. And I think without therapy I really wouldn't have the opportunity to do that, so I'd be forever completely subjugated by these experiences. I wouldn't be working and I wouldn't be having a relationship like I do. And I wouldn't, yeah, I wouldn't be here really. I think I might, might not have survived if I hadn't have had the opportunity. Not even just like the therapy now 'cos it's more recent, but just someone therapeutic, someone to actually to see the sense, even support workers, Network for Change, they were - and the Hearing Voices Group - they were like huge 'cos they were the first people that really said, "There's a meaning here, there's something, this isn't just an illness randomly grabbing you and dragging you like a demon into hospital where other people make you better. There's something here". And I think other people seeing that before you're ready to see it is so key. *Encouraged professional that participant to understand meaning of psychosis*
- 01.03.35: (C:72:1) And I needed that stuff to feel ready for this therapy. 'Cos imagine getting me to this kind of therapy like 8 years ago. God, I would have thought the therapist was nuts. The first time that someone mentioned that the voice might be representative of an abuser - my abuser - I was really angry at them. So I wasn't ready for it. Still not entirely ready for it. *wouldn't have been ready for therapy in first stage of recovery.*
- And presumably, that would feel like a really frightening notion. *understands abusive voice not as internalised abuser, but expression of the experience of abuse*
- 01.04.00: (C:73:1) Yeah, definitely. I think the way I get around that isn't the abuser's in me, or anything like that, 'cos I think that feels horrible. But I think the abuse, the powerlessness, that's got the voice and that voice remembers what people have told me. *understands abusive voice not as internalised abuser, but expression of the experience of abuse*
- The experience.
- 01.04.18: (C:74:1) Yeah, and that's the way I can get around it without feeling that I'm carrying round these abusers, abusive things. And I think that's ok... Yeah it's challenging, but I suppose I'm conscious of time.... Yeah, properly Horrible.
- Shall I pause it now?
- 01.04.42: (C:75:1) Yeah.

Participant C - Interview Part 2

- So Rachel, we were just saying that following on from the previous interview that the starting point of the second interview would be talking in a bit more detail about the process of the therapy that you've been through and where that first started.

Counsellor not able to deal w/

0:26: (C:76:1) Cool. There's probably some bits of therapy I might not have told you about - I can't remember which ones I've sort of talked about because I think I've been in counselling a lot of different times during my life. Like at university I saw a counsellor and that was because I was self-harming and struggling and the GP kind of encouraged me to go and see someone. They got a bit freaked out, because although I didn't tell them about the voices and my beliefs they knew that something wasn't quite right, so I saw them maybe four times before they said I think you really need to see a psychiatrist. So that was quite short-lived.

- And you weren't able to speak about the voices and some of your beliefs.

1:10: (C:77:1) No, not at all, so....

- Why not do you think?

1:13: (C:78:1) I don't know, I think I just I'd been so used to keeping secrets for my whole life, that the idea of talking to someone about it just seemed really alien. It never occurred to me, it wasn't like I was going, "I really want to tell them but I'm scared to", it's just yeah, it just seemed strange that I would even mention it so the only thing I could talk about was the self-harm and the feelings of anxiety and sort of my mood 'cos they were the sort of acceptable things you could talk about as a student. But I think other people around me know, knew that something was a little more off than that.

- Was there something that a therapist could have done at that point that would have helped you to have talked about all of those things, or was that too early for you?

2:07: (C:79:1) I don't know, it's hard to say in retrospect. I think there were little things I can remember her doing that, that kind of perhaps made it harder for me to settle. I think 1) we didn't see each other enough, because obviously as soon as she realised it was something she felt she wasn't able to deal with, she then got rid of me, which was probably because she just couldn't, it just felt like she wasn't sure what to do. So that wasn't good. Because obviously there's no chance to build up a relationship. I think maybe keeping seeing me would have been a good thing.

2:42: (C:80:1) But also I think she was, she, I think she found the way that I responded to the trauma. I told her a bit about some of the traumas that I'd been through and she found it strange that I talked in a very, almost like matter of fact and/or jokey way about them. Not jokey like making giant jokes, but I think I talked about them either quite matter of factly, or with a lightness and a kind of a smile, and I think she found that a bit disturbing 'cos she's say it just didn't feel congruent and I could get what she means 'cos I've witnessed people doing that but it's just, yeah, they were my first attempts to communicate some of the stuff that had happened to me and I guess I didn't feel particularly that it was that she understood. And I think before I build a relationship with a therapist, it takes me a long time to really feel there's some trust there, so I take spend a long time sussing it out. And those kind of things are blocks for me. I need to feel that people really get why I would speak in that way about stuff, so I think I expect quite a lot from my therapists. And she might have

Needs to establish trust w/ therapist.

dealt with the problem

serious distress

about voices

Counselling theory modality wasn't able to

been able to do it, if we'd seen each other over a longer period of time, but just not enough. And also I think I had a whole lifetime of not telling anybody, so it would have taken quite a long time to get the point where telling someone was ok.

4:15: (C:81:1) Other thing though, she could have asked - thinking about it, 'cos actually it was only a couple of years later when I told the psychiatrist about it and the only reason I told him was 'cos he asked the question and I don't think anyone had ever asked about voices or beliefs or unusual things that had happened to me. It just hadn't come up 'cos everyone assumed it was depression. So maybe if she'd have asked I might have said something. Mmmm I hadn't thought about that, yeah simple things.

It's easier
had asked
about voices,

4:41: (C:82:1) So after her I had a little bit of CBT, 'cos a psychiatrist put me to an anxiety management CBT thing.

might
have
spoken about
them.

- This was after you had received a diagnosis of (schizophrenia)-

4:53: (C:83:1) These were all before. So initially, this psychiatrist was treating me for anxiety and depression 'cos I hadn't told him. This was up in Sheffield when I was still a student, so he referred me to an anxiety management programme that I couldn't actually attend 'cos I was too anxious! So then I had individual CBT with a psychologist, and again I had maybe 2 sessions before she realised something was not quite right. And I wasn't eating or kind of washing at that stage, so that's when she mentioned about potentially sectioning if I didn't sort of get help and speak to and sort of ...

initially
treated
for (A)
(D)
with CBT

- Get help. Wasn't she providing help?

5:34: (C:84:1) Yeah, I think it was 'cos, I don't remember the exact context of it 'cos I think I was quite confused back then, but I think it was something like she thought I needed to be in hospital and if I didn't sort of, yeah, it's a really strange context, 'cos of course I was seeing her so I was engaging, but if I didn't sort of do that she was getting to the point of considering recommending that I get sectioned 'cos of self neglect because I wasn't looking after myself. I could never imagine having that conversation with a psychologist 'cos they don't section you, I didn't know that at the time, but I think she'd picked up that something wasn't quite right and was trying to get me to say whatever it was. As it was it kind of freaked me out and I think I told my parents that I wasn't coping and they came and moved me back to Leicester, which is where I saw a psychiatrist and they actually asked the question about the unusual experiences and I told them - not everything, but I blurted out quite a lot and that's when I got the diagnosis.

psychologist
thought
(C) should
be
sectioned
for self-
neglect.

- What led them to ask that question in the first place?

was described full
'symptoms' received
diagnosis.

06:42: (C:85:1) I think I was probably looking very confused and sort of - yeah, I think I was probably looking really distracted and quite distressed and I was struggling. Because at that point I had really sort of intense beliefs about aliens and being followed and I was seeing things and hearing things and it was all very, very intense. But I was also quite disconnected so I'd struggle to kind of look at people and kind of, my parents wondered, when they came to pick me I do remember just kind of



book, I'm going to hold to this book and make sure we don't deviate from the book and you're going to fit into the book and it'll all be fine." //

- Why is that different from working with someone in a peer support relationship?

11:28: (C:90:1) I think... mmmmm, it is that difference- and it's not necessarily peer support, 'cos peer support can be done prescribed like that, and it can be. so maybe it's not actually the difference between peer support and sort of bad CBT. I think it's whether you feel that the person understands the whole of you or is trying to understand the whole of you and whether you feel seen, and that you're kind of - I think the idea, or my idea is that whether it's any kind of therapy, including just the peer support version of support, is that you as the person are sort of setting the direction and the other one's acting as a guide. They might not know the territory that well, and they might not know where you're going, but they're kind of giving you a bit of trust to direct it, and they've just got some skills and tools and understanding that can help you, but it's not, it's about you and where you're going, not about them and their comfort zone. Although that does influence it so it's not as clear cut. But yeah I think the feeling of being seen and having - that it's relevant to what you're living. 'Cos if it's just a tick box and just a kind of a work that you're going through that doesn't relate to where you're at, it's not that helpful.

- Maybe there's also something about the therapist setting themselves up in the position of the one who's going to lead, which if they're not confident in their ability to do that, once you've already created that precedent, and you put somebody else in the position of being the person who's going to follow or have something done to them, then maybe that's an element to it as well?

13:23: (C:91:1) Yeah I think so - again it's like if you go into the jungle and the person who is leading you into the jungle has like a kind of bluffer's guide to the jungle book and he's going, "Right this is a tree". That's not going to give you lots of faith in their ability to help you through this. //

13:40: (C:92:1) I think also just, it's a common thing for me - certainly in my early days of therapy - is to try and please the therapist and the whole me feeling that I needed to actually produce an example and work through it the way they wanted to, didn't help. I know in a lot of my therapy that's been a theme for me where I've felt I needed to do what they wanted of me. It's only recently I've been able to say, "No this is my therapy here, if I'm not happy with this I can kind of go in a different direction and say it." It's taken me a long time to even mention unhappy things to therapists, I've been a very compliant - probably a pleasure to treat. The problem is that every therapist probably I imagine has the sense they've never really got to the bottom of what's going on with me, because I do everything they say and I'm quite jovial and I will talk about the deep stuff, but still that final bit of connection doesn't happen and I don't really move. Until recently, so... //

- Do you feel the therapists that you're mentioning in that context were able to see you were doing that?

Attending to the
other
Being listened
to felt
therapeutic.
feeling
to fit
into
therapist's
comfort
zone did
not.

Rigidity
of method
inexperience
are a bad
contribution

Desire
to please
therapist
and not.
Speak mind
made things
worse.

took a lot of
trust to speak
about unpleasant
things.

wondering round in circles and just finding it really hard to understand what was going on around me and kind of just feeling – yeah almost like in a dream. So my behaviour had changed enough for people to start questioning what was going on.

7:37: (C:86:1) And it might have just been actually the psychiatrist 'cos they always cover the basics and I was an 18, 19 year old girl who is, like dropped out of university and looks a bit weird, it's quite a standard psychi question to go, "Hmmm have you ever had any of these things?" Because they'd be querying if I was having an episode of psychosis. Yeah, so could be the context, so probably a bit of me looking a bit weirder and a bit of them, me fitting their box because it's quite common for young people to kind of go through that.

8:12: (C:87:1) I think going into the medical sort of system and getting the diagnosis eventually through that, that sort of halted the therapy, so I'd have little bits of counselling, but then there was no counselling or therapy while I was an in patient or – even when I was sort of discharged, I was discharged to a CHMT, ~~so I had a nurse who tried to do a bit of CBT for psychosis for me but out of a book.~~ And yeah, it didn't make any sense to me at all. It just felt like why are you working through a book with me that's full of really cheesy ideas that don't relate to me at all, and you're giving me homework. It just, it didn't feel helpful, it felt very box – tick box approach to it.

- What were the cheesy questions?

9:02: (C:88:1) I can't really remember, so it's more of an impression than a definite – again it was a long time ago. But it was those kind of examples – someone says something and you then, yeah, you have the thought and then the feeling and then the voice or whatever and just trying to and again you think, "What else could they have meant by that?" And it was a very kind of – ok you had to give an example, so I had to try and think from the week before what example have I had when I've had a strong reaction and my voices have got worse and relate something, so I'd usually give a false example 'cos I couldn't think of anything. So it's almost like we were working from a false starting point which was my fault 'cos I should have just said I can't think of anything but I think I felt that I had to produce a concrete thing that we could work through. And then we'd work through it by – yeah, what were you feeling, what were you thinking, what else could they have meant and yet it was coming from a completely disjointed place because it wasn't a real example and my examples wouldn't have fitted into that but there was no talking around it or kind of exploring what it meant to me – it was conveyor belt it just felt really prescribed.

- So in trying to fit in with the therapist's need to deliver a therapy, you ended up with something that seemed to be quite far removed from the truth.

10:35: (C:89:1) Yeah definitely, and I think the other thing was 'cos she was a CPN and didn't know – like many of the CPNs who haven't been trained in CBT for psychosis. She didn't appear to be very confident in what she was doing. So yeah, I guess I didn't have much trust that she knew what she was doing either – but it wasn't in that nice way of the peer support movement where you're both kind of finding your way together, and it feels like you're moving together towards something – hopefully. It was more, "I don't really know what I'm doing here, I'm a bit nervous, I've got a

Can't.

psychiatrist looking for symptoms; found them.

becoming an inpatient walked me therapy.

inexperienced therapist did not help.

→ P33
→ P34

Mechanistic approach to therapy was too rigid and made participant feel had to fit in to model.

14:48: (C:93:1) I think ~~I~~ think she probably had this un-named, weird feeling, 'cos it was shortly after that that I ended up diagnosed with BPD for a while - borderline personality disorder - not because of her, I was an inpatient again, they again had this feeling that something wasn't quite right and couldn't quite understand what it was. So

I went for about 6 - 8 months diagnosed with BPD before I got the schizophrenia thing back again, and once I got labelled with that during the course of my work with her, she changed dramatically 'cos - again my perception of this is that it gave her a word for the un-named feeling that she had and then she could put me in a box and say this is personality difficulties coming out here, this is why I feel uncomfortable and why we're not getting very far with it. And then it changed so she was talking much more about my relationship with my family and my mum and making what I felt were quite a lot of judgements about me, but she seemed a lot more comfortable than when I got relabelled. yeah, I can't even remember what she was like then.

- If her approach was to work with CBT, perhaps there wasn't a facility to name that feeling. With another mode of working - for instance, psychoanalytically - one might call it a transference, or one might be able to name that thing and then be able to work with it.

16:25: (C:94:1) Or even tell someone about it, yeah I think - again its all guesswork but if you've got if you're a nurse in a CMHT and you've got an unusual feeling about a client, what do you do with that? You could tell your supervisor but then your supervisor might or might not be understanding about that and you might also feel de-skilled. I'm sure I provoked a lot of de-skilly feelings in people back in those days. So, yeah, it's just not set up for working and I think no one really recognised how complex my issues were back then. I think if they knew what my issues were it would be quite obvious that I needed someone that had that kind of support and could name those un-named feelings and work them through themselves. But looking back it was obvious that that just wasn't going to work for me, those kind of very superficial approaches, it wasn't really going to get me far.

17:21: (C:95:1) Also that CBT gave me a few tricks, not that therapist, well that nurse, but the actual CBT therapist I saw for the anxiety in Sheffield, even though I saw her a few times, the one thing that I've carried with me from her - I think you pick up little bits from lots of people - was just the traps of thinking. She gave me just a hand out of ten traps that you could fall into and I recognised a lot of them and it didn't, it wasn't like a hallelujah moment, but throughout the rest of my life I've often thought about catastrophising and the different things we can get into. I've not thought about it in a pure CBT way, but I've kind of looked at a lot of my ways of thinking about situations and tried to think of differences and why I do that. Yeah, it gave me - that little thing was useful and feeling that she cared as well, 'cos I think she did care. So not all bad.

- Being in a therapeutic relationship with someone who was interested in you, who cared about you sounded important.

18: 30: (C:96:1) Yeah I think so, 'cos at that time I didn't care about myself and I didn't feel - I think I probably felt that there was so much about myself I was hiding I felt a bit fake. Because I wasn't telling people about my past, I wasn't really telling people about my voices, I didn't feel I really existed and I had all these aliens and

everything and it was just all my interaction with the people - just yeah, it wasn't me and my whole inner...

24
Therapist
had not
facility
to
relate to
unspoken
dynamics

*
Changing
diagnosis
changed
rel.

→ P41
→ P26

Difficult
to name
Trans.
fed into
diagnosis
& treatment.
And lack
of ability to
name it.

Previous
has to be
useful bit
from previous
therapy

Feeling
therapist
cared/was
interested
helped

Send out letter to participants, inviting their feedback on the research

Dear *****

I hope all's well.

It has taken quite some time, but the research which you took part in is now complete. Thank you again for the time you gave me, and your willingness to share your story.

Now that all of the participants' stories have been edited and collated and the thesis has been completed, I would very much like to get some feedback from you on the following two areas:

- 1) How you feel your story has been represented.
- 2) The overall narrative that your story is presented within.

When you have a moment, if you were able to read the attached document '**PsychD research extract**' and email me any thoughts you have, I would be very grateful indeed. The central thrust of the thesis contrasts, what I've referred to as, the 'personal meanings' of those with lived experience of 'schizophrenia' with the 'medical meaning' of those treating it. This argument highlights the importance of 'personal meaning' in both 'breakdown' and recovery from 'schizophrenia', and as such, your feedback will be a fitting way for me to appraise the findings.

A note of explanation. The **PsychD research extract** document contains the thesis cover sheet, the abstract (so you can see the overall context), and the glossary of terms, before coming to the findings, which are shown in Chapter 6 of the thesis. This starts with an overview of the chapter and a rationale for the composite depiction' form that has been used to present the findings.

All participants are anonymous. For your reference, you are Participant (*).

I'm pleased to say that an extract of the research will be appear as a book chapter called '**Personal versus medical meanings in breakdown, treatment and recovery from 'schizophrenia'**' in *Critical Psychotherapy, Psychoanalysis and Counselling*, which is being published by Palgrave Macmillan this spring/summer. This book chapter contains a very reduced version of the argument put forward in the thesis. I've also attached a draft copy of the book chapter here, in case you wanted to read more.

Please can I ask you not to circulate either of these documents.

I look forward to hearing from you when you have a moment.

Best wishes

Tom

Participant feedback

Participant A

Lacanian psychoanalysis - this went on past time of interview: female. As befits a highly trained psychoanalyst she didn't diagnose as much as discuss whether I was sure about my own explanation and would let me know if she didn't agree based on what I said but would explore that.

That is up to the interview

For the record, after the interview, I had to stop the Lacanian therapy as it was twice weekly sessions and as things got more overwhelming with (*illness of close family member, there was no longer time for the therapy*).

At the time of the interview I was facilitating a hearing voices group in B*****. I had to stop that too, and I now attend one for my own health in L*****.

I have since had 12 sessions of counselling with a male counsellor that did deal with my voices and was helpful briefly, and am now doing Maastricht interview with a female CPN, that is the best thing I have done. However I have also attempted my own form of voice dialogue and walking/ psychogeographical therapy which I hope to write about in the future as self-help, using getting lost then a kind of apophenic Freudian dream interpretation dialectics (reversing the discounts the voices do dialectically based on what geographical direction turning I do, including coming across physical obstructions, to find my way again). I have no idea if it cures me but it's great fun! Things to do when you are psychotic.

Participant D

Really glad to hear that you have finished your thesis and it is a fine piece of work. Really liked the approach of looking at the material subjectively and it was real good to hear that the rest of the participants are on the road to recovery except one but this was over all heart warming as you do not hear so many stories of people in recovery when they get our diagnosis. I feel that you handled my material very well, remaining factual to the subjective material that I brought, and even though empirical, you handled it sensitively and not clinically... Even though painful as always to talk about my experiences, I feel that this is one of the few times that it has been handled in a very non-judgmental and is true to me, and encourages me to speak up some more.

Thanks for the experience.

Participant E

Thank-you for sending this, it was interesting to read. I feel that my narrative has been accurately represented and that the overall narrative is a useful contribution to understanding the experiences of people diagnosed with "psychosis" and our contact with mental health services. In many ways I think I have moved forward in terms of accepting my experiences since we met, so it was helpful for me to be able to compare how I felt then with how I feel now... I am no longer planning to try and

reduce medication any time soon, but I have been accessing private psychodynamic psychotherapy which is helping me to understand myself better. I'm increasingly realising that the voices are not the main problem, and that a lot of my issues come from me and not from them, so I no longer find them as threatening and powerful as I have in the past. I think I feel less weird and different to others and that is helping me to make sense of things that happen in my life.

Participant H

In response to your questions, I feel you represented my story very well. Taking part in your research played a very important part in my ongoing recovery as it wasn't until I had been interviewed by you that I really started exploring my experience of psychosis. I thought at that point that I had already dealt with it (given that it had happened more than twenty years earlier and I had been in therapy for some years by then) but what I had achieved was the courage to announce it publicly... When you interviewed me you got my first complete outpouring of the story of my breakdown and recovery - this started an ongoing process that is still continuing. What has been really helpful about reading your findings is that my narrative is now fairly concrete so reading elements of when it was very new for me has been enlivening. I was also reminded of things I had forgotten I had said.

I think the overall narrative represents my experience very well. I found it moving and, although I know none of your other participants, I feel a connection with them due to the shared experiences you have presented. It's helped me feel less alone with it.

References

- AALTONEN, J., SEIKKULA, J. & LEHTINEN, K. (2011) The comprehensive open-dialogue approach in Western Lapland: I. The incidence of non-affective psychosis and prodromal states. In *Psychosis* Vol. 3, No. 3, October 2011, 179–191.
- ADLER, N. (1997). Purpose in life. In *Psychosocial workgroup*. MacArthur Foundation. <http://www.macses.ucsf.edu/research/psychosocial/purpose.php> [Accessed: 11th of March 2011]
- APA (American Psychiatric Association) (2005) *DSM-IVTR Diagnostic and Statistical Manual of Mental Disorders* (4th edition). New Dheli: Jaypee.
- ALANEN, Y.O. (2009) Can We Approach Patients with Schizophrenic Psychoses from a Psychological Basis? In ALANEN, Y.O., GONZALEZ de CHAVEZ, M., SILVER, A.L., & MARTINDALE, B. (eds.) *Psychotherapeutic Approaches to Schizophrenic Psychoses: Past, Present and Future*. London: Routledge.
- ANDREW, A., KNAPP, M., MCCRONE, P., PARSONAGE, M. & TRACHTENBERG, M. (2012) *Effective Interventions in Schizophrenia: The Economic Case: A Report Prepared for the Schizophrenia Commission*. The London School of Economics.
- ANON1 (1989) A Delicate Balance. *Schizophrenia Bulletin*. Vol.15 (2), pp. 345-346.
- ANON2 (1990) ‘A Pit of Confusion’ *Schizophrenia Bulletin*. Vol.15 (2), pp. 355-359.
- ARENDT, H. (1978) *The Ife of the Mind*. New York: Harcourt, Brace, Jovanovich.
- ATKINS, D & LOEWENTHAL, D. (2004) The lived experience of psychotherapists working with older clients: an heuristic study. *British Journal of Guidance & Counselling*. Vol. 32, No. 4, November 2004, pp493-509.
- AYER, A.J. (1956) *The Problem of Knowledge*. Harmondsworth, Middlesex: Penguin Books Ltd.
- BARHAM, P. (1995) Manfred Bleuler and the understanding of psychosis. In ELLWOOD, J.(ed.). *Psychosis: Understanding and Treatment*. London: Jessica Kingsley Publishers.
- BARKER, P., CAMPBELL, P. & DAVIDSON, B. (eds.) (1999) *From The Ashes of Experience: Reflections on Madness, Survival and Growth*. Philadelphia, PA: Whurr Publishers.
- BATESON, G. (2000) *Steps to an Ecology of Mind*. Chicago & London: Chicago University Press.

- BARNES, M. & J. BERKE (1974) *Mary Barnes: Two Accounts of a Journey Through Madness*, London: Penguin Books Ltd.
- BECK, J. C., & Van der KOLK, B. (1987). Reports of childhood incest and current behavior of chronically hospitalized psychotic women. *American Journal of Psychiatry*. 144(11), pp1474–1476.
- BELL, J. (2005) *Doing Your Research Project: A Guide to First Time Researchers in Education, Health and Social Science*. Berkshire, England: Open University Press.
- BENTALL, R. P. (2005) R.D. Laing: An Appraisal in the Light of Recent Research. In RASCHID, S. (ed.) *R.D. Laing: Contemporary Perspectives*. London: Free Association Books.
- BENTALL, R.P. (2006) 'Schizophrenia Term Use 'Invalid' BBC News [Online]. 9th October 2006. Available from: <http://news.bbc.co.uk/1/hi/health/6033013.stm> [Accessed: 12th December 2012].
- BOEREE, C. G. (2006). *Viktor Frankl*. [Online]. Available from: <http://webpace.ship.edu/cgboer/frankl.html> [Accessed: 3rd February 2014].
- BOLL, D. M. (1999) The application of short-term, time-limited, closed homogenous outpatient psychotherapy group to individuals with schizophrenia: an exploratory clinical study. In *Dissertation Abstracts International: Section B: The Sciences and Engineering*, Vol 59(9-B), Mar 1999. pp. 50-71.
- BOLLAS, C. (2013) *Catch them Before they Fall: The Psychoanalysis of Breakdown*. London: Routledge.
- BOSS, M. (1963) *Daseinsanalysis and Psychoanalysis*. New York: Basic Books.
- BOYLE, M. (2002) *Schizophrenia: A Scientific Delusion?* (2nd edition). Hove: Routledge.
- BRACKEN, P. (2002) *Trauma: Culture, Meaning and Philosophy*. London Wurr Publishers Ltd.
- BRACKEN, P., THOMAS, P., TIMIMI, S., ASEN, E., BEHR, G., BEUSTER, C., BHUNNOO, S., BROWNE, I., CHHINA, N., DOUBLE, D., DOWNER, S., EVANS, C., FERNANDO, S., GARLAND, M.R., HOPKINS, W., HUWS, R., JOHNSON, B., MARTINDALE, B., MIDDLETON, H., MOLDAVSKY, D., MONCRIEFF, J., MULLINS, S., NELKI, J., PIZZO, M., RODGER, J., SMYTH, M., SUMMERFIELD, D. & WALLACE, J. (2012) Psychiatry beyond the current paradigm. In *The British Journal of Psychiatry* 201, pp430–434.
- BRAZIER, C. (2012) Into the wild - vital signs: psychological responses to ecological crisis. In *Self & Society* Vol.40 No.1 Autumn 2012.

- BREGGIN, P. R. (2008) *Brain Disabling Treatments in Psychiatry: Drugs, Electroshock and the Psychopharmaceutical Complex* (Second edition). New York: Springer Publishing.
- BUBER, M. (1970 [1923]) *I and Thou*. New York: Simon and Schuster.
- BURSTON, D. (2000) *The Crucible of Experience*. London: Harvard University Press.
- CHADWICK, P. (2006) Peer-professional first-person account: schizophrenia from the inside – phenomenology and the integration of causes and meanings. *Schizophrenia Bulletin*. Sept 2006: pp.1-8.
- CHADWICK, P. (2009) *Schizophrenia: The Positive Perspective, Explorations at the Outer Reaches of Human Experience* (2nd edition). Hove: Routledge.
- CLARK, J. (1988) Duet: The experience of the psychologically androgynous male. (Doctoral dissertation, Union for Experimenting Colleges and Universities) *Dissertation Abstracts International*, 49, 235-B.
- CLARKE, C.J.S. (1996) *Reality Through the Looking Glass*. Edinburgh: Floris Books.
- COLEMAN, R. (2000) *Recovery, An Alien Concept?* Gloucester, UK: Handsell.
- COOPER, M. (2003) *Existential Therapies*. London: Sage.
- COTTON, T. (2008) *What relationship, if any, is there between the way we treat people and 'The Treatment' in Psychotherapy?* Unpublished MSc Psychotherapy and Counselling thesis.
- COTTON, T. & LOEWENTHAL, D. (2011) Laing and the treatment is the way we treat people. In Loewenthal, D (ed.) *Post-existentialism and the psychological therapies: Towards a therapy without foundations*. London: Karnac.
- COTTON, T. & SANDBERG, N. (2011) Using video as therapy, post-existentially: Experiences of 'schizophrenia' – a Therapeutic film project. In *Phototherapyeurope Learning And Healing With Phototherapy*. Brahea Centre for Training and Development, University of Turku, Finland.
- COURSEY, R.D., KELLER, A.B. & FARRELL, E.W. (1995) Individual psychotherapy and persons with serious mental illness: The clients' perspective. In *Schizophrenia Bulletin*, Vol 21(2), 1995. pp. 283-301.
- CRAIG, E. (1978) The heart of the teacher: A heuristic study of the inner world of teaching. (Doctoral dissertation, Boston University) *Dissertation Abstracts International* 38, 7222A.
- CRAIG, E. (1988) Introduction: Daseinsanalysis: a quest for essentials. In *The Humanistic Psychologist*, 16:1, pp1-21.

- CRAIG, E. (2007) From Daseinsanalysis to Taops psychotherapy: integrating psyche and spirit. In *International Federation for Psychotherapy Newsletter*. December 2007, pp5-15.
- CROMBY, J. & HARPER, D. J. (2009) Paranoia : a social account. In *Theory & Psychology* 2009 19. pp335-361
- DAMASIO, A. (1999). *The feeling of what happens: Body and emotion in the making of consciousness*. New York: Harcourt Brace.
- DESCARTES, R. (1962 [1637]) *A Discourse on Method: Meditation and Principles*. (Trans. Veitch, J.). London: J.M. Dent and Sons.
- DILLON, J. (2009) Fifty Stories: Jacqui Dillon. In ROMME, M., ESCHER, S., DILLON, J., CORSTENS, D., MORRIS, M. (eds.) *Living with Voices*. Ross-on-Wye: PCCS Books.
- DILLON, J. (2012) Recovery from 'Psychosis'. In GEEKIE, J., RANDAL, P., LAMPSHIRE, D. & READ, J. (eds.) *Experiencing Psychosis: Personal and Professional Perspectives*. London: Routledge.
- DILLON, J. & MAY, R. (2002) Reclaiming Experience. *Clinical Psychology*. Vol 17. pp25-7.
- DILTHEY, W. (2010) *Wilhelm Dilthey: Selected Works, Volume II: Understanding the Human*. Makkreel, R. & Rodi, F. (eds.). Princeton: Princeton University Press.
- D'OMBRAINE HEWITT, R. (2012) Therapy was Life-Changing. In *Healthcare Counselling & Psychotherapy Journal*. Oct 2012, Vol. 12 Issue 4, pp.30-33.
- DORMAN, D. & PENNEY, C. (1999) Being together in the therapeutic relationship. In *International Journal of Psychotherapy*, Vol 4(1), Mar, 1999. pp. 11-31.
- DUDLEY, R., BRABBAN, A. & TURKINGTON, D. (2009) Cognitive behavioural therapy for psychosis. In ALANEN, Y.O., GONZALEZ de CHAVEZ, M., SILVER, A.L., & MARTINDALE, B. (eds.). *Psychotherapeutic Approaches to Schizophrenic Psychoses: Past, Present and Future*. London: Routledge.
- ELLWOOD, J. (1995) Introduction. In ELLWOOD, J. (ed.) *Psychosis: Understanding and Treatment*. London and Brighton, Pennsylvania. Jessica Kingsley Publishers.
- FINE, G. (1992) *On Ideas: Aristotle's Criticism of Plato's Theory of Forms*. Oxford: Oxford University Press.
- FINLAY, L. (2009) Debating Phenomenological Research Methods. *Phenomenology & Practice*. Vol 3, No1, pp6-25.

- FONAGY, P., TARGET, M., GERGELY, G. & JURIST, E.J. (2002). *Affect Regulation, Mentalization and the Development of the Self*. New York: Other Press.
- FRANKL, V.E. (2011) *Man's Search for Ultimate Meaning*. London, Sydney, Auckland: Rider Books.
- GARRETT, D. (1997) *Cognition and Commitment in Hume's Philosophy*. New York: Oxford University Press.
- GEE, J. P. (1999) *Discourse Analysis: Theory and Method*. London: Routledge.
- GEEKIE, J., RANDAL, P., LAMPSHIRE, D. & READ, J. (eds.) (2012) *Experiencing Psychosis: Personal and Professional Perspectives*. London, Routledge.
- GEEKIE, J. (2012) The uncertainty of being: Existential aspects of the experience of Psychosis. In GEEKIE, J., RANDAL, P., LAMPSHIRE, D. & READ, J. (eds.) *Experiencing Psychosis: Personal and Professional Perspectives*. London: Routledge.
- GELSO, C. & J.A. CARTER (1994) 'Components of the Psychotherapy Relationship: Their Interaction and Unfolding During Treatment' *Journal of Counseling Psychology* Vol. 41, No. 3. pp. 296-306.
- GELVEN, M. (1989) *A Commentary on Heidegger's Being and Time*. Revised edition. DeKalb, Illinois: Northern Illinois University Press.
- GENDLIN, E (1962) *Experiencing and the Creation of Meaning: A Philosophical and Psychological Approach to the Subjective*. New York: The Free Press of Glencoe.
- GENDLIN, E (1978) *Focusing*. New York: Everest House.
- GEORGI, A., KNOWLES, R., & SMITH, D. L. (eds.). (1979) *Duquesne Studies in Phenomenological psychology*. (Vol. 3). Pittsburgh: Duquesne University Press.
- GILL, J. H. (2000) *The Tacit Mode: Michael Polanyi's Postmodern Philosophy*. New York: State University of New York Press.
- GOLDACRE, B. (2012) *Bad Pharma: How drug companies mislead doctors and harm patients*. London: Fourth Estate.
- GREENWOOD, D., & LOEWENTHAL, D. (2005) The use of 'Case study' in psychotherapeutic research and education. In *Psychoanalytic Psychotherapy* Vol. 19. No 1, pp.35-47.

- GREENWOOD, D. & LOEWENTHAL, D. (2011) On learning to work with someone with a label: Some post-existential implications for practice, theory, and research. In LOEWENTHAL, D. (ed.) *Post-existentialism and the psychological therapies: Towards a therapy without foundations*. London: Karnac.
- GUBRIUM, J., & HOLSTEIN, J. (1997) *The New Language of Qualitative Method*. New York: Oxford University Press.
- GUY, A., THOMAS, R., STEPHENSON, S. & LOEWENTHAL, D. (2011) *NICE under scrutiny: the impact of the National Institute for Health and Clinical Excellence guidelines on the provision of psychotherapy in the UK*. UKCP Research Unit, Research Centre for Therapeutic Education, Roehampton University, UK.
- HARROW, M.L. & JOBE, T.H. (2013) Does long-term treatment of schizophrenia with antipsychotic medications facilitate recovery? In *Schizophrenia Bulletin*. 2013 Sep, 39(5), pp962-965.
- HAWKA, S. (1986) The experience of feeling unconditionally loved. (Doctoral dissertation, Union for Experimenting Colleges and Universities, 1985). *Dissertation Abstracts International*, 46, 4385-B.
- HEIDEGGER, M. (2008 [1926]) *Being and Time*. (Trans. Macquarrie, J. & Robinson, E.) Harper. London: Perennial Modern Classics.
- HEPPNER, P. P., KIVLIGHAN, D. M., Jr., & WAMPOLD, B. E. (1992). *Research Design in Counseling*. Pacific Grove, CA: Brooks/Cole.
- HORNSTEIN, G. (2009) *Agnes's Jacket: A psychologist's search for the meanings of madness*. New York, NY: Rodale Books.
- HOWARTH-WILLIAMS (1977) *R.D. Laing, His Work and its Relevance for Sociology*, Routledge & Kegan Paul: London.
- HOUSE, R. (2010) *In, Against and Beyond Therapy: Critical Essays Toward a 'Post-Professional' Era*. Ross-On-Wye: PCCS Books.
- HUME, D. (1961) *A Treatise of Human Nature Vol 1*. London: J.M. Dent and Sons.
- HUSSERL, E. (1960) *Cartesian Meditations. An Introduction to Phenomenology*. (Trans. Cairns, D.). The Hague: Martins Nijhoff.
- JANSSEN I., KRABBENDAM L., BAK M., HANSSEN M., VOLLEBERGH W., & De GRAAF R. (2004) Childhood abuse as a risk factor for psychotic experiences. In *Acta Psychiatr Scand* 2004; 109: 38–45.
- JOSEPH, J. (2003) *The Gene Illusion*. Ross-on-Wye: PCCS Books.

- JOSEPH, J. (2004) Schizophrenia and heredity: why the emperor has no genes. In READ, J., MOSHER, L. & BENTALL, R.P. (eds.). *Models of Madness* Routledge, Hove.
- KANT, E. (1929 [1781]) *Immanuel Kant's Critique of Pure Reason*. (Trans. Kemp Smith, N.). London: Macmillan Press, Ltd.
- KARON, B. P. (2003) The Tragedy of schizophrenia without psychotherapy. In *Journal of The American Academy of Psychoanalysis und Dynamic Psychiatry*. 31(1), pp89- 118.
- KIRK, S. A. & KUTCHINS, H. (1992) *The Selling of DSM: The Rhetoric of Science in Psychiatry*. New Brunswick, New Jersey: Transaction Publishers.
- KIRSCH, I. (2009) *The Emperor's New Drugs: Exploding the Antidepressant Myth*. London: Bodley Head.
- KOEHLER, B. (2012) *Relational Psychosis Psychotherapy: A Neuropsychanalytic Model*. Unpublished paper given to The International Society for Psychological and Social Approaches to Psychosis (ISPS), 2012 International Conference, Perugia, Italy.
- KUHN, T.S. (1996) *The Structure of Scientific Revolutions* (3rd ed.) Chicago, London: University of Chicago Press.
- LAW, J. (2006) *Big Pharma: Exposing the Global Healthcare Agenda*. New York: Carroll & Graf Publishers Inc.
- LAING, R.D. & A. Esterson. (1964) *Sanity, Madness and the Family*. Tennessee: Kingsport Press.
- LAING, R.D. (1965) *The Divided Self*. London: Penguin Books Ltd.
- LAING, R.D. (1967) *The Politics of Experience and The Bird of Paradise*. Middlesex: Penguin Books Ltd.
- LAING, R.D., H. PHILIPSON & A.R. LEE (1969) *Interpersonal Perception: A Theory and a Method of Research*. London: Tavistock Publications Limited.
- LAING, R.D. (1976 [1969]) *The Politics of the Family*. London: Pelican.
- LAUVENG, A. (2012) *A Road Back From Schizophrenia*. New York: Skyhorse Publishing, Inc.
- LESZCZ, M., YALOM, I.D. & NORDEN, M. (1985) The Value of Inpatient Group Psychotherapy: Patients' Perceptions. In *International Journal of Group Psychotherapy*. Vol 35(3), July 1985. pp.411-433.

- LEVANDER, S. & WERBART, A. (2003) Different views of a psychotic breakdown - complementary perspectives of a bewildering experience. *Psychoanalytic Psychotherapy*. Vol 17(2), Jun, 2003. pp. 163-174.
- LEVINAS, E. (1994) *The Levinas reader*. HAND, S. (ed.). Massachusetts: Basil Blackwell Inc.
- LOEWENTHAL, D. (2007) Introducing relational research. In *Case Studies in Relational Research*, LOEWENTHAL, D. (ed.), London, Palgrave Macmillan.
- LOEWENTHAL, D. (2008) Post Existentialism as a Reaction to CBT? In LOEWENTHAL & HOUSE (eds.). *Against and For CBT: Towards a Constructive Dialogue*. Ross-on-Wye: PCCS Books.
- LOEWENTHAL, D. (2008a) Introducing post-existential practice: an approach to wellbeing in the 21st Century. In *Philosophical Practice*, October 2008, 3.3: pp316-321.
- LOEWENTHAL, D. (2011) On the very idea of post-existentialism. In LOEWENTHAL, D. (ed.) *Post-existentialism and the psychological therapies: Towards a therapy without foundations*. London: Karnac.
- LOEWENTHAL & HOUSE (2008) An exploration of the criticisms of CBT. In LOEWENTHAL & HOUSE (eds.). *Against and For CBT: Towards a Constructive Dialogue*. Ross-on-Wye: PCCS Books.
- LOEWENTHAL, D. & SNELL, R. (2003) *Post-modernism for Psychotherapists*. Hove: Brunner-Routledge.
- LONGDEN, E., MADILL, A., & WATERMAN, M. (2012) Dissociation, Trauma, and the role of lived experience: toward a new conceptualization of voice hearing. In *Psychological Bulletin*, Vol. 138, No. 1, pp28–76.
- MASLO, A. (1956) Self-actualizing people. A study of psychological health. In MOUSTAKAS (ed.) *The Self* (pp.160-194) New York: Harper & Brothers.
- MASONI, P., MUCCI, M., SALVADORI, P., DINI, P. & MURATORI, F. (2000) Efficacy evaluation of therapeutic group experiences with chronic psychotic patients. In *Minerva Psichiatrica*, Vol 41(2), Jun, 2000. pp.93-101.
- MAUTNER, T. (1996) *Dictionary of Philosophy*. London: Penguin.
- MCCARTHY-JONES, S. (2012) *Hearing Voices: The Histories, Causes and Meanings of Auditory Verbal Hallucinations*, Cambridge: Cambridge University Press.
- MCLAUGHLIN, T. (2000) *Psychology and Mental Health Politics: a Critical History of the Hearing Voices Movement*. Unpublished Phd.

- MCLEOD, J. (2001) *Qualitative Research in Counselling and Psychotherapy*. London: Sage Publications Ltd.
- MCLEOD, J. (2003) *Doing Counselling Research* (2nd edition), London: Sage Publications Ltd.
- METCALF, A. (2012) Stepping into the archipelago. *New Directions in Psychotherapy and Relational Psychoanalysis Journal*. 6, pp122-136
- MISHLER, E.G. (1991) *Research Interviewing: Context and Narrative*. Harvard: Harvard University Press.
- MITCHELL, J. (1986) *The Selected Melanie Klein*. Harmondsworth: Penguin.
- MOHELSKY, H. (1994) A Whack on the Head. In *Psychosocial Rehabilitation Journal*. Vol 18(2), Oct, 1994. pp.35-41.
- MOSHER, L. R., GOSDEN, R. & BEDER, S. (2004) Drug companies and schizophrenia: Unbridled capitalism meets madness. In READ, J., MOSHER, L & BENTALL, R.P. (eds.). *Models of Madness*. Hove: Routledge.
- MOSKOWITZ, A. (2005) Are psychotic symptoms traumatic in origin and dissociative in kind? Summary of a paper presented at the 22nd International Society for the Study of Dissociation (ISSD) conference, Toronto, November 2005.
- MOUSTAKAS, C. (1961) *Loneliness*. New York: Prentice Hall Press.
- MOUSTAKAS, C. (1968) *Individuality and Encounter*. Howard A. Doyle Publishing Company, Cambridge Massachusetts.
- MOUSTAKAS, C. (1981) Heuristic Research. In REASON, P. & ROWAN, J. (eds.). *Human Enquiry: A Sourcebook of New Paradigm Research*. Chichester, New York: John Wiley & Sons.
- MOUSTAKAS, C. (1990) *Heuristic Research: Design, Methodology, and Applications*. California: Sage Publications, Inc.
- MOUSTAKAS, C. (1994) *Phenomenological Research Methods*. California: Sage Publications, Inc.
- NCCMH (National Collaborating Centre for Mental Health) (2010) *The NICE Guideline on Core Interventions In The Treatment And Management Of Schizophrenia In Adults In Primary And Secondary Care*. (Updated Edition). London: The British Psychological Society and The Royal College of Psychiatrists.

- NEWMAN, J.M., TURNBULL, A., BERMAN, B. A., RODRIGUES, S. & SERPER, M R. (2010) Impact of Traumatic and Violent Victimization Experiences in Individuals With Schizophrenia and Schizoaffective Disorder. In *The Journal of Nervous and Mental Disease*. October 2010 - Volume 198 - Issue 10, pp699-781.
- NOLL, R. (2000) *The Encyclopaedia of Schizophrenia and Other Psychotic Disorders* (2nd edition). New York: Facts on File, Inc.
- O'BRIEN, B (1960) *Operators and Things*. London: Elek Books.
- PARKER, I., GEORGACA, E., HARPER, D., MCLAUGHLIN, T. & STOWELL-SMITH, M. (1995) *Deconstructing Psychopathology*. London: Sage.
- PARKER, I. (1999) Deconstruction and psychotherapy. In PARKER, I. (ed.) *Deconstructing Psychotherapy*. London: Sage.
- PELTIER, B. (2010) *The Psychology of Executive Coaching*. London, New York: Routledge.
- PICKEN, A L., BERRY, K., TARRIER, N. & BARROWCLOUGH, C. (2010) Traumatic Events, Posttraumatic Stress Disorder, Attachment Style, and Working Alliance in a Sample of People With Psychosis. In *Journal of Nervous & Mental Disease* October 2010 - Volume 198 - Issue 10 - pp 775-77
- POLANYI, M. (1969) *Knowing and Being: Essays by Michael Polanyi*. (GRENE, M. ed.). Chicago: University of Chicago Press.
- POLANYI, M. (2009) *The Tacit Dimension*. Chicago and London: University of Chicago Press.
- POPPER, K. (2002) *Conjectures and Refutations*. London: Routledge Classics.
- POTTER, J. & WETHERELL, M. (1987) *Discourse and Social Psychology: Beyond Attitudes and Behaviour*. London: Sage.
- RAPLEY, M., MONTCRIEFF, J. & DILLON, J. (2011) Carving Nature at its Joints? DSM and the medicalization of everyday life. In RAPLEY, M., MONTCRIEFF, J. & DILLON, J. (eds.). *De-Medicalizing Misery: Psychiatry, Psychology and the Human Condition*. London: Palgrave Macmillan.
- READ J., PERRY B., MOSKOWITZ A. & CONNOLLY J. (2001) The contribution of early traumatic events to schizophrenia in some patients: A traumagenic neurodevelopmental model. *Psychiatry* 2001; 64: 319–45.
- READ, J., GOODMAN, L., MORRISON, A.P., ROSS, C.A. & ADERHOLD, V. (2004) Childhood trauma, loss and stress. In READ, J., MOSHER, L & BENTALL, R.P. (eds.). *Models of Madness*. Hove: Routledge.

- READ, J. & BENTALL, R. P. (2012) Negative childhood experiences and mental health. In *British Journal of Psychiatry*. 200. pp89-91.
- RODRIGUEZ, A. (1985) A Heuristic-phenomenological investigation of Mexican American ethnic identity. (Doctoral dissertation, Union for Experimenting Colleges and Universities, 1984). *Dissertation Abstracts International*, 46. 313-B.
- ROE, D. & LYSAKER, P. (2012) The importance of personal narratives in recovery from psychosis. In GEEKIE, J., RANDAL, P., READ, J. & LAMPSHIRE, D. (eds.) *Experiencing Psychosis: Personal and Professional Perspectives*. London: Routledge.
- ROGERS, C. (2004) *On Becoming a Person*. London: Constable.
- ROMME, M. & ESCHER, A. (1993) *Accepting Voices*. London: MIND.
- ROMME, M., ESCHER, S., DILLON, J., CORSTENS, D., MORRIS, M. (eds.) (2009) *Living with Voices*. Ross-on-Wye: PCCS Books.
- ROMME, M. (2009) Important Steps to Recovery with Voices. In ROMME, M., ESCHER, S., DILLON, J., CORSTENS, D., MORRIS, M. (eds.) *Living with Voices*. Ross-on-Wye: PCCS Books.
- ROSS, C. A. & READ, J. (2004) Antipsychotic medication: myths and facts. In READ, J., MOSHER, L & BENTALL, R.P. (eds.). *Models of Madness*. Hove: Routledge.
- SALK (1983) *Anatomy of Reality: Merging of Intuition and Reason*. New York: Columbia University Press.
- SCHORE, A. (2012) *The Science of the Art of Psychotherapy*. New York, London: W. W. Norton & Company.
- SCHULTZ, D. (1983) *The experience of self-reclamation of former catholic religious women*. (Doctoral Dissertation, Saybrook Institute, 1983). *Dissertation abstracts international*, 44, 926-B.
- SELA-SMITH, S. (2002) Heuristic research: a review and critique of Moustakas's Method. *Journal of Humanistic Psychology*, 42: pp53-88.
- SHORE, D. (2006) Ethical issues in schizophrenia research: a commentary on some current concerns. *Schizophrenia Bulletin*. Jan 2006, 32(1): pp26–29.
- SILVERMAN, D. (2005) *Doing Qualitative Research*. (Second edition). London: Sage.
- SMAIL, D. (2005) *Power Interest and Psychology: Elements of a Social Materialist Understanding of Distress*. Ross-On-Wye: PCCS Books.

- SMITH, J. A., FLOWERS, P., & LARKIN, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research*. London, Sage.
- SOLMS, M., & TURNBALL, O. H. (2011) What Is Neuropsychanalysis? In *Neuropsychanalysis*. 2011, 13 (2), pp1-13.
- SOMMER, R. (2003) The Use of Autobiography in Psychotherapy. In *Journal of Clinical Psychology*. Feb 2003, Vol. 59 Issue 2, pp.197-205.
- SPINELLI, E. (2005) *The Interpreted World: an Introduction to Phenomenological Psychology*. London: Sage.
- STANTON, B. & DAVID, A. (2000) First Person Account of Delusions. *Psychiatric Bulletin*, Vol 24(9), Sep, 2000. pp.333-336.
- STEINBECK, J. & RICKETTS, E.F. (1941) *The Sea of Cortez*. New York: Viking Press.
- STOLLER, R. (1997) *Splitting: A Case of Female Masculinity*. New Haven and London: Yale University Press.
- TARNAS, R. (1996) *The Passion of the Western Mind*. London: Random House.
- There is a Fault in Reality*. (2010) Film. Directed by Tom Cotton. [DVD] UK: Tigerlily Films.
- TRUMBULL, M. (2005) Qualitative Research Methods. In Taylor, G. R. (ed.). *Integrating Quantitative and Qualitative Methods in Research*. Maryland: University Press of America, Inc.
- THOMAS, P. & BRACKEN, P. (2005) *Postpsychiatry*, Oxford University Press, Oxford.
- THOMAS, R. & LOEWENTHAL, D. (2007) A case of ‘Empirical Phenomenological Research’: What the experience of Counselling/psychotherapy is when the client understands they have a learning difficulty. In LOEWENTHAL, D. (ed.). *Case Studies in Relational Research: Qualitative Research Methods in Counselling and Psychotherapy*. Basingstoke: Palgrave Macmillan.
- THOMAS, S. (2011) Open-Dialogue Therapy: can a Finnish approach work elsewhere? *Issues in Mental Health Nursing*. 32:613, p613-613.
- TOTTON, N. (2012) ‘Nothing’s out of order’” toward an ecological therapy. In RUST, M-J., & TOTTON, N. (eds.). *Vital Signs: Psychological Responses to Ecological Crisis*. London: Karnac.
- VIAMONTES, G. I. & BEITMAN, B. D. (2009) Brain Processing Informing Psychotherapy. In GABBARD, G. O. (ed.). *Textbook of Psychotherapeutic Treatments in Psychiatry in Institutional Settings*. Arlington VA: American Psychiatric Publishing Inc.

- WAGNER, P.S. (1996) First person account: A voice from another closet. In *Schizophrenia Bulletin*, Vol 22(2), 1996. pp. 399-401.
- WAMPOLD, B. E. (2001). *The Great Psychotherapy Debate: Models, Methods, and Findings*. Hillsdale, NJ: Erlbaum.
- WATKINS, P. (2008) *Mental Health Practice: A Guide to Compassionate Care*. Philadelphia: Butterworth, Heineman, Elsevier.
- WHITAKER, R. (2010) *Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and the Astonishing Rise of Mental Illness in America*. New York: Crown.
- Wild Strawberries*. (1957) Film. Directed by Ingmar Bergman. [DVD] Sweden: Tartan Films.
- WINNICOTT, D. (1965). *The Family and Individual Development*. New York, London: Tavistock Publications.
- WINTER, D. (2006) Avoiding the fate of the dodo bird: the challenge of evidence-based practice. In Loewenthal, D. & D. Winter, (eds.). *What is Psychotherapeutic Research?* London: Karnac.
- WHO (World Health Organization) (1992) *The ICD-10 Classification of Mental and Behavioural Disorders*. Geneva: World Health Organization.